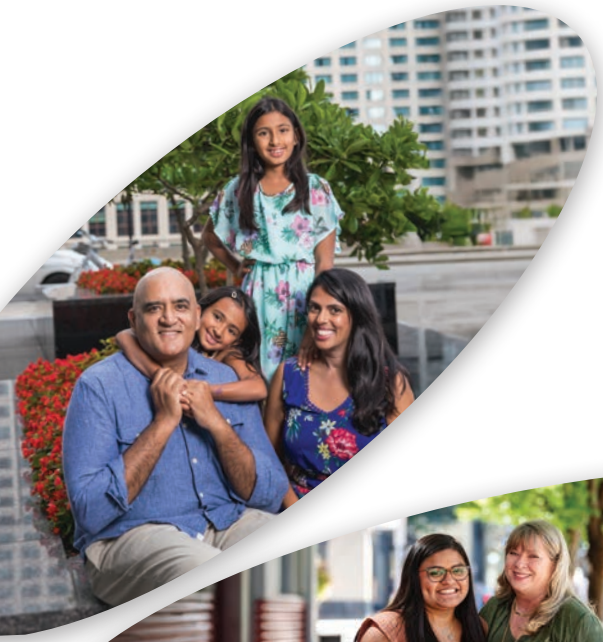
Platelet Disorder Support Association

Empowering ITP Patients

Living with ITP

ANSWERS TO COMMON QUESTIONS



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INTRODUCTION

Each year, the Platelet Disorder Support Association (PDSA) receives hundreds of questions about immune thrombocytopenia (ITP) and other platelet disorders from patients, family members, and health care providers including doctors, nurses, and medical students. This publication is a sampling of some of the questions we have received and our replies to those questions.

This booklet is intended to provide assistance and hope for those living with ITP. To learn more about ITP, including how this rare autoimmune platelet disorder is diagnosed, treated, and to be aware of the latest ITP research and support for this condition, please refer to the list of other publications we offer (page 31) or visit *pdsa.org*.

As knowledge expands, new information about ITP and other platelet disorders often arises each year. We do our best to ensure the information in each booklet is up to date. We update our free downloadable booklets available online on a frequent basis. Therefore, for the most up-to-date information, please review our website at *pdsa.org/booklets*.

LIVING WITH ITP

DIAGNOSING ITP

Q How is a diagnosis of ITP made?

A Unfortunately, diagnosing ITP is not straightforward. ITP is known as a disease with a "diagnosis of exclusion," meaning that other potential causes of thrombocytopenia should be ruled out before a diagnosis of ITP (also referred to as primary ITP) is made. However, it is not possible to rule out all possible underlying causes of thrombocytopenia, especially right at diagnosis. As a result, some individuals may be mislabeled as having ITP when in fact they could have an inherited thrombocytopenia (genetic cause), or a secondary ITP.

There are two distinct types of immune thrombocytopenia (ITP): primary and secondary. Primary ITP is when an individual has a diagnosis of immune thrombocytopenia (low platelet count due to an immune cause) in absence of any identifiable immune disorder. Secondary ITP is when a low platelet count is due to an underlying immune disorder. This may be an underlying viral infection, rheumatologic disorder such as lupus or rheumatoid arthritis, primary bone marrow disorder such as chronic lymphocytic leukemia, or an underlying immune disease such as common variable immune deficiency.

Inherited platelet disorders (IPDs) are another known cause for a low platelet count. IPDs are not considered to be primary or secondary ITP but rather 'genetic' conditions. IPDs or "congenital platelet disorders" may be present at birth or early in childhood and may be associated with other medical problems. Some inherited platelet disorders are quite complex and affect many parts of the body while others are very limited to affecting only the platelets. It is not uncommon for patients to be diagnosed initially with ITP, and later learn they have an IPD, sometimes years after the initial ITP diagnosis. For more information, visit: *pdsa.org/patients-caregivers/disease-information/genetics*.

Q Is it still routine for ITP patients to receive a bone marrow biopsy at their initial diagnosis? If not, at what point would you recommend one?

A It is not routine to perform a bone marrow biopsy at diagnosis. These are typically only performed when there are unusual features about the presentation of the ITP or on blood tests. However, some physicians are more inclined to perform bone marrow biopsies in patients over the age of 60 because there is a higher likelihood of identifying other things that could assist with understanding their condition.

LOOKING FOR AN ITP SPECIALIST

Q I am looking for an ITP doctor — someone who wants to identify the source, not just address the symptoms of low platelets. How do I find a good ITP doctor?

A It is important when you or your child has a rare disease, like ITP, to be treated by someone familiar and up to date with knowledge about the particular disorder. While many, but not all, hematologists are ITP specialists, often individuals with stable ITP are managed by their primary care provider, such as a family doctor. Not all doctors are experts in ITP. Therefore, it is advisable that you or your child find a hematologist who is knowledgeable about ITP and who can communicate with your doctor about how to effectively manage and monitor the condition, which includes more than simply focusing on the platelet count (called thrombocytopenia). Your family doctor may not be able to identify the source of thrombocytopenia, but that is where having an expert hematologist is helpful and often essential.

Q How can I find a hematologist in my area who is a specialist in treating my ITP?

A Since hematology is a large and complex field of medicine, hematologists often specialize in a particular disease group. Many physicians who practice hematology are also trained in oncology (called Hematology-Oncology) and it is important to find specialists who devote a considerable portion of their time to hematology, not oncology. PDSA has a database of hematologists who specialize in treating ITP patients (both pediatric and adult). You can find more information on the PDSA website on the "Find an ITP Doctor" page at *pdsa.org* or contact the PDSA office.

There are many reasons why thrombocytopenia can occur, and it may not be possible to determine right away why someone developed ITP. A trained hematologist specializing in ITP will rule out other common causes of thrombocytopenia before diagnosing a patient with ITP. If ITP is the most likely diagnosis, the hematologist may start you on a first-line therapy, such as corticosteroids or intravenous immunoglobulin (IVIG) depending on the platelet count and bleeding symptoms. Generally, if the platelet count is >30,000 and there are no bleeding symptoms, the hematologist may recommend that treatment is not started. Rather, the physician may prefer a "watch and wait" method.

Below are suggestions to find a hematologist who specializes in treating ITP and similar diseases:

- Contact PDSA (*pdsa@pdsa.org* or 440-746-9003). We maintain a list of specialists who may be able to help. We also have many ITP Support Groups around the country and some members may recommend hematologists in their area.
- Search the "Find a Hematologist" portion of the American Society of Hematology's website.
- Locate the largest teaching hospital near you and ask for the head of hematology or the specialist in non-malignant hematology to make a recommendation on which ITP expert is in your area or is reasonably close by.
- Contact the Best Doctors organization, a fee-based service.
- Search the membership list of The American Medical Association.

Visit *pdsa.org/find-doctor* to find an ITP expert and to link to the above suggestions.

QUESTION ABOUT ACUTE VERSUS CHRONIC ITP

Q **Could you please explain the difference between 'acute' vs. 'chronic' ITP and how this relates to adults and children?**

A ITP that goes away on its own after a few months used to be referred to as 'acute,' and ITP that lasted longer was referred to as 'chronic.' Now, we refer to ITP in three different stages, or phases: newly diagnosed ITP (first 3 months), persistent ITP (lasting 3-12 months), and chronic ITP (lasting more than one year). Approximately 80% of adults with ITP will develop chronic ITP. In contrast, most children with ITP usually see their ITP resolve spontaneously after a few months and only about 20% develop chronic ITP.

QUESTIONS TO ASK A NEW ITP SPECIALIST/DOCTOR

Q **What specific questions should an ITP patient ask their new doctor?**

A The following is a list of suggested questions to assist with selecting a healthcare provider and to enhance communication.

About Provider Experience and ITP Management in General:

How much experience have you had treating patients with ITP?

How many ITP patients do you treat each year?

Are you affiliated with any research group or hospital that specializes in non-malignant hematology?

In what situations would you offer treatments (both first line and second line) to an ITP patient?

Do you support shared decision making in terms of management and treatment? Shared decision making (SDM) is a collaborative process where patients and their healthcare providers work together to make decisions about care. SDM involves considering a patient's values, preferences, and circumstances, along with the best available scientific evidence and the provider's expertise.

Do you welcome a patient who researches the disease and treatments?

Are you open to second opinions?

What is your opinion about patients including complementary or alternative treatments?

When should I update my doctor on changes to my ITP such as new symptoms or bleeding?

When should I go to the hospital with my ITP; what is considered an emergency?

About the Treatments:

Are you familiar with the current updated ASH ITP guidelines about treatment?

Are you familiar with the updated International Consensus Report on ITP?

What tests will you be ordering?

What are the goals of treatment?

Is there a specific platelet count target you are trying to achieve for me?

What will these tests show you?

Are there any risks with these tests?

What types of treatments are available for ITP adult patients?

What types of treatments are available for ITP pediatric patients?

What treatments would you recommend trying first? What would you recommend next if that treatment fails?

At what platelet count should I be worried?

How long will I need this treatment?

How will the treatment be administered?

What are the criteria for discontinuing the treatment?

Is this treatment designed to raise my platelet count temporarily or permanently?

What will you recommend next if the treatment fails?

What are the side effects of the treatment?

For which side effects should I contact you?

Are there any precautions that can be taken to minimize the side effects?

Will I develop other medical problems from this treatment?

How will you monitor the treatment progress?

Are there any changes that I should make to my lifestyle as a result of ITP or the treatment?

For more information, please visit *pdsa.org/newly-diagnosed*.

PLATELET COUNT FLUCTUATIONS

Q **I'm at the beginning stages of ITP and diagnosis; are a larger number of immature platelets observed? And when people's platelet counts fall, is it generally a slow or a fast decline?**

A When patients first present with bleeding symptoms – petechiae, bruises, blisters in the mouth – and are given a therapy such as IVIG, doctors can observe their platelet counts improving in a matter of days. After 3 or 4 weeks, the effects of the IVIG may wear off and the platelet counts may drop again. However, this time the bleeding symptoms are not present. This occurs because the bone marrow, where platelets are produced, has had a chance to catch up and create younger, larger, and more effective platelets. Likewise, when patients are given steroids, one immediate effect is that platelets are mobilized from the spleen quickly back into the blood. An alternative reason why bleeding symptoms disappear without the rise in platelet count is that the blood vessels are lined with closely sealed endothelial cells, but the space between those cells loosen when an individual has a low platelet count. Steroids work to reseal these specialized cells to stop bleeding events before platelet counts have a chance to rise.

Q What is the effectiveness of immature platelet fraction (IPF) on determining whether the ITP is due to inadequate platelet production or increased destruction?

A There have been studies to examine the use of immature platelet fraction (IPF) in ITP, however, there is not a consensus on whether it can be used diagnostically. There is a thought that if an ITP patient has a low IPF, they may respond less well to a specific class of ITP treatments, the TPO-RAs, though this is not conclusive.

Currently, the use of IPF is more of an academic interest and researchers are trying to understand what it means and how we can use it more beneficially for patients. Information on IPF is collected from patients to understand their ITP holistically, but it is not yet used to guide the choice of therapy.

CAUSES OF ITP

Q What are the possible causes of autoimmune diseases like immune thrombocytopenia (ITP)?

A It has been proposed that viruses, vaccinations, medications, and unidentified environmental agents might cause the immune system to mount an attack on platelets or other parts of the body.

WHEN IT'S NOT ITP

Q Does PDSA have any patient information for families about inherited thrombocytopenia?

A Yes, we do! While inherited thrombocytopenia disorders are rare, there are some families that appear to have multiple family members with ITP. Many inherited thrombocytopenia disorders can present with just a low platelet count, making it very difficult to distinguish it from primary ITP. As a result, we created a space on our website to provide information about other causes of a low platelet count. This information can be accessed by visiting: *https://pdsa.org/patients-caregivers/disease-information/when-its-not-itp.html*. We also created a section on our PDSA website to provide information on genetics and common hereditary thrombocytopenia conditions. This information can be accessed by visiting: *pdsa.org/genetics*. In addition to inherited thrombocytopenias, there are also secondary causes of ITP, such as other autoimmune conditions. You can learn more about other conditions that could present like ITP by visiting: *pdsa.org/patients-caregivers/disease-information/when-its-not-itp*.

Q Is it myelodysplastic syndrome (MDS) or ITP? Can you have both?

A It is possible for one person to have both MDS and ITP, though it would be unusual. MDS is a disease that occurs mostly in elderly populations and is a bone marrow disorder. An analogy is that the thermostat built into the bone marrow that controls the production of red blood cells, white blood cells, and platelets is altered by typically genetic causes. In ITP, this thermostat is not necessarily affected. Rather, there is an increased rate of platelet destruction in the body after the platelet leaves the bone marrow. It is possible that the diagnosis of ITP be confused with MDS. However, ITP only affects platelets. If you also have, for example, a low red blood cell count, it is important for the physician to inquire further if there is another explanation for the low platelet count. In these cases, a bone marrow biopsy may help with the diagnosis. One reason that steroids and IV immunoglobulins (IVIG) are still used as first-line therapies for ITP is because true ITP typically responds to either of these therapies, at least initially. If someone who presents with a low platelet count does not respond to these therapies, it is possible that their low platelet count is caused by something else rather than ITP.

Q What is cyclic thrombocytopenia?

A Sometimes, cyclic thrombocytopenia can look a lot like ITP. Cyclic thrombocytopenia is named this way because the low platelet count fluctuates greatly and can come and go over periods of time, sometimes being completely normal. However, the immunologic basis of these cyclical patterns has not been well researched. Women may experience cyclical thrombocytopenia due to hormonal changes. Sometimes, the cyclical patterns may not be physiological, they could be due to the inappropriate use of thrombopoietic agents, a type of treatment available for ITP patients. For example, if a patient's platelet count is responding well to Nplate™, they may be taken off therapy. However, this risks their counts dropping back down right after. Doctors should not take a patient off treatment immediately after they respond, but rather slowly decrease the dose. Patients can also develop antibodies that can destroy their anti-platelet autoantibodies (called anti-idiotype antibodies), which may provide another explanation to cyclic thrombocytopenia.

Conventional ITP Treatment

ITP TREATMENT GUIDELINES

Q **Are there professional medical guidelines or International Consensus Reports on ITP?**

A The American Society of Hematology (ASH) published updated guidelines used in North America for how to guide management of ITP patients. These guidelines should be reviewed and carefully considered by doctors treating ITP patients. It is important to know that the guidelines are updated regularly. Please ensure you and your ITP doctor are aware of the most current version of the ASH ITP guidelines. The PDSA website will also include the most recent version for your educational purposes.

The International Consensus Report was also updated, shortly after the last ASH guidelines were published. While this international consensus report is not considered a medical guideline, it is used as a guide to manage ITP patients alongside the ASH guidelines. The International Consensus Report is practical and comprehensive and is based on expert experience rather than limited published medical evidence and is a great resource to be aware of.

The current version of both the ASH ITP Guidelines and the International Consensus Report can be accessed through the PDSA website by visiting: *pdsa.org/healthcare-professionals-researchers/hcp-resources.html*.

TREATING ITP

Q **I have lived with ITP for 10 years now. I had my spleen removed and was fine until last year. The past year I have been battling this condition, with two hospitalizations. What information does PDSA have on new progress with the cure of this disease? Is there a way to be 'proactive' instead of 'reactive'? As I do not want to go back to a hospital for more treatment, what can I do to prevent issues with ITP?**

A Relapse of ITP can be scary and can elicit a multitude of emotions; you are not alone. Researchers and clinicians are getting close to finding therapies that work long-term, stabilizing the platelet count. However, an actual 'cure' at this time is not yet available. For some people with ITP, their disorder may be a short-lived experience. However, ITP can return even years later. A few individuals who experience a relapse in their ITP following a brief remission after having a splenectomy may have an accessory spleen. That means

they may have 'extra' spleen tissue that was not removed during the surgery and is functioning like a normal spleen. Additional surgery may be helpful if this is the case.

The approved treatments available for ITP are not curative, but some people do find that they provide long-lasting results. To date, treatments can be thought of as being emergent or preventative. Emergent meaning to rapidly raise the platelet count to a higher level to stop bleeding. Preventative meaning the use of therapies that can provide more long-term results to reduce the incidence or bleeding while stabilizing the platelet count and improving quality of life. To learn more about conventional (standard medicines) treatments for ITP, please visit: *pdsa.org/treatments/conventional.html*.

To better assist clinicians and patients with ITP, PDSA developed one-page treatment fact sheets on all approved ITP therapies. These fact sheets can also be used to compare the 'pros' and 'cons' of different treatment options during shared decision discussions with your ITP doctor. To download a treatment fact sheet, please visit: *pdsa.org/treatments/conventional.html*.

ROLE OF PLATELET COUNTS AND SYMPTOMS IN TREATMENT

Q **Has the normal range to measure platelets changed recently? The lab where I go to check my platelet count said the range is from 130,000 to 400,000. However, I thought it was 150,000 to 450,000. What is the correct range?**

A We are not aware of changes in the range of normal platelet count. For most labs, the normal platelet count is 150,000 to 400,000 per microliter of blood. While thrombocytopenia means the platelet count has fallen below 150,000 per microliter of blood, a diagnosis of ITP is often not made until a person's platelet count consistently falls below 100,000. This is because there are many causes of mild thrombocytopenia; having a platelet count between 100,000 – 150,000 may be normal for some people. Or their low platelet count could be due to another medical condition. Platelet counts between 100,000 – 150,000 should be monitored; some people in this range may develop ITP or other blood disorders that require treatment.

Q **My platelet counts generally run between 20,000-40,000. I have no bleeding problems and I'm not being treated. But I have terrible fatigue that's getting worse each year. Assuming this is due to the ITP, is fatigue enough of a reason to start treatment?**

A Treatment isn't always based on platelet counts. Fatigue is a common experience among those living with ITP, however the exact cause of the fatigue has not yet been identified. Many physicians believe that if you feel fatigued enough – even if you're not bleeding and your platelet count is above a certain number – treatment may be appropriate to improve your overall quality of life.

One important consideration is that if you start treatment and your platelet counts improve, this may not always improve your fatigue. We don't fully understand why fatigue occurs in ITP, but research shows it may be related to inflammation throughout the body, not just due to platelet counts. There are many factors that can be causing someone's fatigue.

CHRONIC ITP AND A LOW PLATELET COUNT

Q **I have a high school student recently diagnosed with ITP. The doctor she saw said her case "wasn't that bad" and didn't offer any treatment because her platelet count was at 40,000. However, she struggles with fatigue, and it is affecting her schoolwork. Can PDSA offer us some help?**

A Fatigue is very common in ITP. The exact underlying cause is unknown, but it is a symptom many ITP patients struggle to deal with. It would be helpful for the student to discuss their fatigue level with their hematologist, including the extent of their fatigue, how often it occurs, and if it correlates to any particular activity. For most patients, the common treatments for ITP incur more side effects and often fail to correct the fatigue. PDSA has information to help deal with fatigue and other physical and emotional issues related to ITP, including a booklet on *Coping with ITP* and a booklet on *ITP in Teens*. See *pdsa.org/products-a-publications/free-materials.html.*

It's common to worry about a low platelet count. However, PDSA's medical advisors always suggest that the symptoms (such as bleeding, fatigue, overall health-related quality of life) are more important than the actual platelet count itself when deciding options for management. The decision on 'when to treat' can vary between different ITP doctors, even with medical guidelines available.

Any or all of the following are factors often considered when deciding to recommend treatment or changing dosage of current treatment:

- (Adults) When the platelet count falls below 30,000, however, this will vary between patients
- (Adults and Children) When treatment for bleeding is required
- (Adults and Children) When quality of life (QoL) is impaired
- (Adults and Children) When preparing for surgery
- (Adult and Children) When timely follow-up isn't possible and/or living too far from a treating hospital
- (Adult and Children) Other medical situations in which a higher platelet count is required

All treatments have possible benefits, risks, and limitations to balance. One limitation of first-line therapies (like prednisone) is that they may only work for a short time period and are usually only prescribed for a short interval of time. For some individuals with ITP, they may require second-line therapy, such as rituximab or thrombopoietin receptor agonists (TPO-RAs).

It may also be helpful to register with PDSA and receive our monthly and quarterly publications detailing the latest information about ITP. *pdsa.org/about-us/contact.html*

HELP WITH TREATMENT COSTS

Q Can PDSA help with treatment costs?

A Although PDSA cannot offer direct assistance programs for help with patient medications, we can tell you that most pharmaceutical companies offer patient assistance programs to help patients receive the medicines they provide.

You will need to contact the pharmaceutical company that manufactures the drug you are interested in to find out if you are eligible for assistance. PDSA has a free patient insurance and assistance information booklet on our website: *pdsa.org/booklets.* It offers links to many organizations that may be able to assist with treatment and medication for ITP.

EXPERIENCE WITH IVIG FOR CHILD WITH ITP

Q Thank you, PDSA, for the tremendous response and support that you gave to our family when our child had her bad experience with IVIG. We were going to take her to the hospital yesterday, but she fell asleep, so we decided to let her rest. That evening she woke up with another bad headache, so we gave her medication, and she fell asleep again and ended up sleeping all night. We were prepared and expecting to take her to the hospital today.

A most welcome sight was our child walking toward us this morning looking much better. She is definitely on the upswing. Our question remains: should we stick with IVIG, after such bad side effects for her? We are nervous to try it again. We are grateful to be part of your wonderful support group with such caring people.

A IVIG use can lead to side effects such as severe headaches and flu-like symptoms that can last several days. There are a number of reasons this can occur. Sometimes, the IVIG is infused too quickly or pre-medication (with Benadryl for instance) was not started before the infusion. Sometimes something called "serum sickness" can occur following IVIG use. Other times the problem is unavoidable despite optimal medical care.

Not all IVIG product formulations are the same — some have ingredients included that other formulations do not. A patient can have a reaction to one IVIG product and still be fine with another. It is recommended that you write down the manufacturer name and ask for the lot number on the bottle. If you decide to try IVIG again for your child, ask your doctor if there is a different IVIG product available to try.

You have to be your own, or your child's, best advocate. It is important to ask your child's hematologist or medical provider what to expect following IVIG use, and to explain everything that is monitored during the infusion. Be sure to ask about pre-medicating your child before the IVIG is started, including ensuring you are properly and well hydrated. For more information on how to minimize adverse effects of IVIG, visit: pdsa.org/images/IVIGtips.pdf.

The doctor may need to include an IVIG plan in your child's chart ahead of time. For additional information, visit: *pdsa.org/treatments/conventional/immunoglobulins.html*. For some patients who have experienced unpleasant side effects following IVIG use, other treatment options may be explored.

TPO-RA SWITCHING AND TAPERING

Q **I had chronic and refractory ITP for years. The only thing that has worked for me is a TPO-RA agent; however, this past year it hasn't been working as well and my platelet count is low again. Would you recommend trying another TPO-RA agent?**

A Yes, switching is encouraged. If a hematologist recommends treatment with a TPO-RA and it does not work (assuming the dose and administration are correct), it is perfectly reasonable to consider trying another TPO-RA rather than assuming another would not provide beneficial results. One of the most recent TPO-RA agents, called avatrombopag (Doptelet), has been around for less time compared to the other TPO-RA agents: eltrombopag (Promacta/Revolade) and romiplostim (Nplate). Therefore, there is less research available on the success of switching to another TPO-RA if there isn't a great response achieved using avatrombopag.

Q **Is it okay to drop eltrombopag (Promacta/Revolade) dosage from 3 times a week to once weekly if the platelet count is over 50,000? Or should it be tapered more slowly?**

A It is generally better to taper TPO-RAs (or really any other medication) slowly. Making sudden changes with these treatments may run the risk of dropping a patient's platelet count very low. Therefore, tapering slowly avoids the risk of extreme fluctuation in platelet counts, which can cause a lot of stress for patients.

H. PYLORI AND ITP

Q **Do you have any information pertaining to ITP and *Helicobacter pylori (H. pylori)* bacteria?**

A Depending on where you live, it may be more commonplace for your doctor to rule out an *H.pylori* infection at the time of your, or your child's, ITP diagnosis. To read a short discussion about *H. pylori*, visit *pdsa.org/antibiotics.html.*

PLAQUENIL TREATMENT

Q **I have several autoimmune disorders including diabetes, ITP, lupus and rheumatoid arthritis. My ITP is under control with Plaquenil® (hydroxychloroquine sulfate USP, an antimalarial drug). It raised my platelet count and has kept the count up for the last few years. I haven't come across anyone with the same conditions. Are there other ITP patients on Plaquenil® as well?**

A Some of the autoimmune issues you indicated you have could cause a low platelet count, and thus be responsible for your ITP. When ITP is caused by an underlying immune issue, it's referred to as secondary ITP. Or you could have an inborn error of immunity, such as an immune dysregulation disorder driving your low platelet count. These possibilities are sometimes treated differently than primary ITP. In many cases, treating the underlying cause helps improve the platelet count. That could be why you are taking and have received some benefit from Plaquenil®. A number of patients with lupus have their platelet count rise when Plaquenil® or other therapies are started for the lupus. To read more about secondary causes of ITP, visit: *pdsa.org/patients-caregivers/disease-information/when-its-not-itp.html.*

TREATMENT OPTIONS FOR PATIENTS WHO CANNOT RECEIVE BLOOD PRODUCTS

Q **I have ITP, with a really low count at the moment. I have tried steroids, but it hasn't worked, and I can't have any operations because I will bleed to death. I am a Jehovah's Witness and refuse to have blood transfusions. Is there any other form of treatment that you know of that doesn't involve use of blood?**

A There are treatments for ITP that don't involve blood products. Corticosteroids, rituximab (Rituxan®), fostamatinib (Tavalisse®), romiplostim (Nplate®), or eltrombopag (Promacta®), and many others might help and they are not derived from blood. Sometimes these treatments can be given for a brief period of time to elevate the platelet count to allow for a safe splenectomy procedure. See the Treatments section of the PDSA website at *pdsa.org/treatments.html* and talk with your doctor about treatment options. If you don't already have a hematologist, PDSA has a list of physicians who specialize in ITP.

Splenectomy

SPLENECTOMY FOR ITP AND ALTERNATIVES

Q **I have ITP and have a low platelet count. IVIG and steroids are not keeping my platelets up. Now my doctor wants to remove my spleen. I have many questions about this. Should I get the splenectomy? What is the success rate of this? How can I avoid having a splenectomy? Would it cure my ITP? What will be the long-term effects of removing my spleen?**

A Splenectomy is one option to treat ITP. However, it does not work for everyone. There are newer very effective non-surgical treatment options for ITP that you may wish to consider with your provider, such as thrombopoietin receptor agonists (TPO-RAs), fostamatinib, and rituximab. The long-term success rate for splenectomy is about 60-70%, but splenectomies may be less successful in people over age 60 and the risk for complications is higher. A splenectomy eliminates the main site of platelet destruction. However, in some patients, platelets can also be destroyed in the liver. When considering a splenectomy to treat ITP, it is very important to discuss the possible risks, benefits, and limitations of the procedure with your doctor.

Having a splenectomy leaves you at risk for three particular types of bacterial infections. Fortunately, vaccines are available to protect against these infections and should be taken prior to the splenectomy. These include polyvalent pneumococcal, meningococcal C conjugate, and H influenzae b (Hib) vaccines. Younger patients may be asked to remain on small daily doses of prophylactic antibiotics. Although rare, severe infections can occur and most patients without their spleens are instructed to rapidly seek medical attention for a fever to initiate a course of antibiotics. Please talk to your doctor about what to do if you get a fever following the surgery should you choose to have a splenectomy. There is also an increased risk of blood clots, especially in the first few months after surgery.

Q I had a splenectomy for my ITP. I have a fever of 101 degrees. Should I call my doctor or take Tylenol to see if I feel better?

A In general, the most common cause of an overwhelming blood stream infection after one has had a splenectomy is from something called pneumococcus, which is a type of strep. The best way to prevent, avoid and treat it are 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 anything happens 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. Even if a fever happens at 3am, you should leave for the hospital immediately. You also need to have a reliable thermometer to monitor your temperature whenever you feel ill even if you do not feel warm. Ideally, when you get to an emergency room, a blood culture would be done, a blood count would be drawn, your blood pressure and other things like your temperature, pulse, respiration (breathing) rate would be assessed and you would get an antibiotic such as ceftriaxone right away. After that you need to be observed. Some physicians recommend antibiotic prophylaxis (usually penicillin) to be taken daily for life after splenectomy.

INDIUM SCREENING TEST

Q I am wondering if you have any feedback from people who have gotten the Indium Screening Test in London. My daughter is over there for part of the summer, and she may need a splenectomy soon. I was wondering is the test worth it?

A Indium scanning is a method of labeling a patient's own platelets with a radioactive substance (low-level radioactive tracers) and reinjecting them back into the patient. Scanning is then done over the liver and spleen to see where the platelets are removed. In a few studies, those with mostly a splenic pattern of platelet destruction had a higher rate of successful splenectomies. Unfortunately, the test is not standardized or available in the U.S. and is only available at a few centers in the world.

PDSA has additional information about splenectomy at: *pdsa.org/treatments/conventional/splenectomy.html.*

PREGNANCY AFTER A SPLENECTOMY

Q I was diagnosed with ITP over two years ago and underwent a splenectomy, which cured the ITP.

I have not had any problems since. Now, I am thinking about getting pregnant; however, I wondered could my prior ITP have any effect? Could my ITP reoccur because of pregnancy or is there any higher risk of that occurring?

A Some women do have reactivation of their ITP during pregnancy irrespective of prior treatment. Although splenectomy may improve and even normalize the platelet count, antibodies against platelets may persist in your circulation, which can cause thrombocytopenia in the mother or child.

Fortunately, most babies with mothers who have active ITP are born with normal platelet counts, or lower platelet counts that resolve to normal in a few weeks. It is important for pregnant moms with ITP to ensure they are being monitored by a hematologist with experience in high-risk obstetrical care and can carry out appropriate maternal and newborn management. For more information, take a look at our booklet on *ITP and the Female Lifecycle* at *pdsa.org/booklets*.

Q Has the experience of treating chronic ITP in pregnancy changed?

A It has changed, but not necessarily in terms of drugs used in pregnancy. There is now more knowledge about the effectiveness of certain therapies, such as thrombopoietin receptor agonists (TPO-RAs), in pregnant ITP patients. The way that is has changed is that we are continuously telling patients that their ITP should not be a reason to not get pregnant. Secondly, we advise patients to ensure they have a high-risk obstetrician that is partnered with their hematologist to deliver at a hospital. Lastly, obstetrical anesthesiologists now have updated guidelines and will allow ITP patients who have platelet counts less than 75,000 to get an epidural – previously, they would not give epidurals if you had a platelet count less than 100,000. We've also learned that a C-section is not always required when someone with ITP gives birth. Lastly, we now know that the baby does not need their platelet count checked prior to birth, rather checking these counts at birth is fine. However, the baby's platelet count will need to be followed in case their counts fall.

Q What is considered remission? If it's having normal levels for a certain amount of time (like 6 months or a year), does it have to be without any medication for it to count as remission?

A Most physicians avoid using the term "remission" in ITP. In diseases like cancer, remission is defined by the absence of disease activity. However, if ITP patients are in "remission," this does not mean the condition is cured. Therefore, it is more appropriate to say that an individual has an adequate (otherwise known as a hemostatic) platelet count either on or off therapy. Some physicians use the term "hematologic remission" with patients, which refers to a drug-free platelet count greater than 100,000/µl. Some ITP experts suggest that patients and physicians should focus on whether an individual has a safe platelet count level and can maintain their lifestyle off therapy.

Vaccines and Illness

CHICKENPOX VACCINE AND CHILDHOOD ITP

Q **My daughter has recovered from ITP after receiving Rituxan®. It has been four years of recovery. Side effects of her past steroid treatments destroyed one eye and her mental growth. I am reluctant to give her any further vaccinations as I believe the chicken pox vaccination caused the ITP. All her vaccinations were held since the chicken pox vaccination. Is there any research about vaccination after recovery from ITP?**

A There are some cases where ITP has been preceded by an immunization, such as for chicken pox. Sometimes, it can appear that the ITP is due to a recent vaccine, however it could be coincidence, or it could be that your child already had a low platelet count that was undetected until the vaccine dropped the count to an even lower threshold. There is no way to predict if your daughter will react similarly to another vaccine. However, you should understand that illnesses (such as the ones vaccines prevent) can also trigger ITP in addition to other serious health concerns. One example of a common vaccine children receive is the measles, mumps, and rubella (MMR) vaccine. Our medical advisors feel that overall the rate of significant immune thrombocytopenia after MMR vaccine is very low, just slightly above the rate of childhood ITP in the general population. If a child has ITP and is clinically stable, often vaccinations are not withheld.

Be sure to discuss these concerns with your child's hematologist or other health care provider before she receives or avoids other vaccines.

FLU VACCINES FOR PATIENTS WITH ITP

Q **I have ITP and wonder whether I should get vaccines, such as the annual flu vaccine?**

A There is no way to predict how your platelet count will respond to any vaccine, including the flu vaccine, even if your platelet count had dropped in past following receipt of another vaccine. Our medical advisors suggest to weigh the risks of the disease (in this case, the chance of getting the flu and dropping the platelet count because of the flu) and the possible risks associated with the vaccine. To help in your decision, you should discuss your concerns with your hematologist. You may find additional information about vaccines at the National Vaccine Information Center,

at their website *nvic.org* and from the US Food and Drug Administration (FDA) vaccine information webpage at *fda.gov/BiologicsBloodVaccines/default.htm*.

COVID-19 VACCINES FOR PATIENTS WITH ITP

Q **Can I receive the COVID-19 vaccine or will my platelet count drop more?**

A Similar to the flu vaccine, it is difficult to predict how one's platelet count will respond to the COVID-19 vaccine. PDSA shared a poster at the American Society of Hematology conference which showed that half of the participants (all who had ITP) had the same platelet count after receiving the COVID-19 vaccine, ~30% experienced a drop in platelet count, and ~15% reported an increase in platelet count. Among those who had a change in platelet count (either decrease or increase), 84% shared that their platelet count returned to baseline within 4 weeks. The abstract for this study can be found here: *pdsa.org/images/HCPresources/3164.pdf*

Studies have also shown that getting infected with COVID-19 can also lead to thrombocytopenia and other health conditions. Therefore, it is still recommended for people with ITP to get the COVID-19 vaccine and ensure that your platelet count is monitored closely for a few weeks following receiving the vaccine. To help with this decision, you should discuss any concerns or worries with your hematologist so you can come to a well-informed decision.

Q **Are there any COVID-19 treatment recommendations for patients who have had a splenectomy whose ITP is in remission but are also at an increased risk of infection due to their splenectomy?**

A It is known that patients who had a splenectomy are at an increased risk of infection by encapsulated bacteria/viruses. This is why, ideally, these patients would receive pneumococcal, meningococcal, and Haemophilus influenza type B (Hib) vaccinations at least 2 weeks prior to their splenectomy.

Those who had a splenectomy do not appear to be at a significantly higher risk of COVID-19 infection. However, it could be worthwhile for patients without a spleen to speak with their physician if they develop an infection with COVID-19 to discuss the option of receiving a medication like Paxlovid. ITP experts certainly encourage all patients to be vaccinated against COVID-19 to prevent infection in the first place.

Q **My son, who is in college, has received prednisone, IVIG, and 2 pulses of dexamethasone over the last 6 months. However, he has been getting sick more frequently. Could the immunosuppressive medication be the reason he's getting sick more frequently?**

A The answer is likely multifactorial. Being in a crowded college dorm may be a contributor. The pandemic has also disrupted the natural rhythm of many viruses in the community, so these viruses may be coming at similar times. However, there is a possibility that these treatments have increased your risk of infection. Since the patient required 2 pulses of dexamethasone in the past 6 months, if the platelet count drops again below 30,000/µl, the next step may be to discuss other treatments that aren't immunosuppressive.

Complementary and Alternative Treatments

Some ITP patients look to complementary and alternative medicine (CAM) treatments to help treat their ITP. CAM refers to non-conventional disease treatments, such as diet and supplement use, either alone or in combination with conventional therapies, to treat ITP.

LOCATING PROVIDERS AND INFORMATION ON CAM

Q **Does PDSA maintain a list of alternative medicine doctors who are recommended for help in treating ITP? Any resource would be helpful.**

A Since many alternative providers are not regulated and are not considered part of the medical system, it could be a liability for PDSA to keep such a list. We do try to provide education and information about complementary and alternative medicines in a non-directive way on our website. For more information you could visit *pdsa.org/diet-lifestyle.html* and *pdsa.org/treatments/complementary.html*. You may also find it helpful to visit the National Association of Naturopathic Physicians at: *http://naturopathic.org/*. Only qualified naturopathic doctors (NDs) are listed. Local health food stores often have message boards of other practitioners in the area. Another helpful national index of practitioners is *healthprofs.com*.

EFFECTS OF DIET ON ITP

Q **My friend's husband has ITP and is on prednisone. His platelet count goes up and down. I think diet has a lot to do with it. Can you tell me if diet or even allergies are important with ITP? Also, please give your expert opinion about fruits and vegetables that could be helpful in raising platelets.**

A We've heard from some people who feel that diet and allergies play a part in managing ITP. Unfortunately, there has not been very much scientific research on the subject. At this time, there is no known diet or therapy that will 'cure' ITP.

There are some foods that have helped individuals relieve some of their ITP symptoms, even improve their platelet count. However, just like traditional (conventional) therapies, what works for one person may not have the same effect on another. For more information on foods that you can safely try or avoid, visit *pdsa.org/treatments/complementary.html* and *pdsa.org/about-itp/warnings.html*.

SUPPLEMENTS TO INCREASE PLATELET COUNT

Q **Can anyone tell me of any supplements that my 14-year-old with ITP can take to help his platelet count to go up? What about taking a fish oil supplement? Is this okay for an ITP patient? What about taking plant oils, such as Evening Primrose Oil, Black Currant Oil, or Borage Oil as a supplement? Are there studies about this?**

A We're heard from many people who feel that diet, supplements, or herbs have made a positive difference in their lives and their platelets. However, we cannot suggest a particular treatment to try, as we are not medical providers. You can read about some of the things that have helped others at *pdsa.org/treatments/complementary.html* and *pdsa.org/treatments/complementary/food-as-a-cure.html* for more information about foods and supplements.

Many drugs, foods, and substances can affect the platelet count and platelet function. We have details on the Warnings page on the PDSA website: *pdsa.org/about-itp/warnings.html.*

In general, if your platelets are above 30,000 or if you don't have bleeding symptoms, it is not as important to avoid these substances. It is important for you to tell your hematologist about all of the things you are taking or considering taking.

Some people also visit a naturopath to help improve their general health and possibly the platelet count along with it.

MACROBIOTIC DIET TO HELP ITP

Q **I've read in your literature about some patients getting better with a macrobiotic diet. What exactly is that diet and how can it help ITP? Are there studies about this? How would I get started if I wanted to try macrobiotics to help my platelets? How do I locate a macrobiotic counselor?**

A Macrobiotics in its simplest form is a diet aimed at restoring and maintaining health by considering the energetic qualities of food. In its more complex form, it is a way of life that considers what we eat, see, wear, where we live, and how we communicate. The macrobiotic diet could be beneficial to those who have ITP because it recommends the

elimination of many foods that can cause allergic reactions. Following the macrobiotic diet may reduce the allergic load on the body and reduces strain on the immune system.

A macrobiotic diet is essentially a non-dairy, vegetarian, high fiber, low fat, whole-foods diet with some added fish. A macrobiotic diet is similar to a Mediterranean or Paleolithic diet, though not identical. In coping with any disease, a healthy diet is important. Some published evidence shows that a whole, natural foods, mostly vegetable-based diet is a healthy choice. No studies have demonstrated specific benefits for ITP patients. Some doctors feel that dairy foods aggravate autoimmune diseases. When deciding to change your diet it is always best to start the changes slowly, so your body has time to adjust.

Coping with ITP

SUPPORT FROM OTHERS WITH ITP

Q **As a patient recently diagnosed with ITP, I would like to talk with someone who has lived through this experience. Is this possible?**

A PDSA offers several ways for you to connect to other people living with ITP. PDSA's ITP Patient Connect program includes more than 65 local support groups across the U.S. and Canada, with in-person and virtual meetings. The annual ITP Conference offers adults, teens, children and families the opportunity to meet and talk with others, including a teen track and Kid's Kamp. Another way to connect with other ITP patients is through the PDSA Discussion group and closed Facebook group. For more information on these opportunities, contact visit *pdsa.org*.

AIR TRAVEL WITH LOW PLATELETS

Q **Is there any advice you could give me about ITP and flying. I have a young child with chronic ITP. We are moving from the UK to Florida this year. Is there anything that could help us before flying in regard to raising her platelets if they are very low? Should we wait until her platelets are high enough for her to fly?**

A Traveling with ITP can be a challenge and a source of anxiety. There is nothing to prevent you or your child from flying with a low platelet count. You may want to ensure you have a plan in place should any bleeding symptoms develop. For instance, consider obtaining medical insurance for your child with ITP when traveling, or taking some corticosteroids with you prescribed by your child's doctor. Some doctors may treat a patient's ITP prior to travel for peace of mind to ensure their platelet count is at a safer level, such as prescribing a short course of corticosteroids or IVIG.

If you are feeling fine and have minimal (or no) symptoms, flying is typically fine for patients even if their platelet counts are low. If a patient has a history of nosebleeds, they can take some tranexamic acid with them just in case.

ALCOHOL CONSUMPTION AND ITP

Q **Is it safe to drink alcohol with a low platelet count?**

A Drinking moderate amounts of alcohol is generally okay. Patients should be aware of whether alcohol is contraindicated with some medications and to avoid regular

heavy alcohol use. Some studies show that alcohol does affect the bone marrow, so patients should definitely be cautious about how much alcohol they are consuming.

GETTING A TATTOO WITH ITP

Q **Can I get a tattoo if I have ITP?**

A Tattoos are not so straightforward because there is a risk of bleeding and damaging the skin. Therefore, at low platelet counts, some physicians are more cautious about an ITP patient getting tattoos.

MARIJUANA USE AND ITP

Q **Is it recommended that individuals with ITP avoid marijuana use?**

A There is not much evidence regarding cannabis use and ITP at this time. Should you decide to try any cannabis product, including marijuana, it is important to disclose this to your medical providers to ensure it will not affect your current ITP treatment.

SUPPORTING FATIGUE IN ITP

Q **What are some suggestions to help decrease an adult's fatigue or loss of energy when they have ITP? My doctor suggests exercising more. However, I'm so exhausted I don't feel like I have any energy to exercise and all I want to do is sleep.**

A There is no standard answer that works for everyone. It is important for your doctor to assesses possible explanations for the fatigue. Does it occur at a certain time of day? Is it due to insomnia from the prolonged steroid use? Have you developed sleep apnea due to weight gain? Is it related to depression symptoms? If fatigue is severely affecting your quality of life, one strategy is prescribed treatment. One therapy, called Modafinil, may be used to help energize patients during the day. Another strategy is to use a treatment called Ritalin at low doses, which can help with alertness.

There are real physiological mechanisms for fatigue that are related to your immune system. Research has shown that fatigue is strongly associated with levels of interleukin-6, an immune hormone that is increased in inflammatory conditions. Exercise may improve fatigue; however, you should focus on those that are compatible with your unique lifestyle and platelet count.

SAFE PLATELET COUNT FOR ORTHODONTIC WORK

Q **My patient has ITP with a platelet count around 60,000. Is it safe for her to undergo an orthodontic treatment with possibility of extractions? What are the contraindications for her during the orthodontic treatment?**

A According to our medical advisors, with a stable platelet count of 60,000, most orthodontic procedures can be done without concerns about uncontrollable bleeding. Uncomplicated extractions can also be performed without additional agents. However, some doctors would prescribe epsilon-aminocaproic acid (a drug used to control bleeding) every 4-6 hours starting the morning of the extractions and for 2-3 days afterward. Careful vigilance after the procedure is recommended.

EXERCISE AND ITP

Q **Has there been any research to prove that regular exercise increases the platelet count?**

A Overall, we have heard from some ITP patients that exercise caused their platelet count to increase. It's important to know, this doesn't happen for all ITP patients, and there is no known research published on this subject. PDSA's Medical Advisor Howard Liebman, MD, said exercise releases more platelets from the spleen and can increase the platelet count. This perhaps is why some people have reported a change in their count following exercise. Exercise also helps promote overall good health and has been shown to improve fatigue and depression.

Note: Please talk to your doctor before starting or increasing your usual exercise regime. There may be safer exercise options depending on your platelet count.

DONATING BLOOD WITH ITP

Q **My ITP has been in remission for four years. Is it okay to donate blood to the Red Cross or Canadian Blood Services?**

A It would be best for you to contact the blood bank directly to ask them who is excluded from donating blood. Many people with autoimmune conditions are not permitted to donate blood because patients may still have some residual antibodies to their platelets even though you are in 'remission'. ITP can recur for some people even years following a period of 'remission' where there are absent

clinical indications of ITP. Most blood banks will have a list of conditions they are unable to accept blood donations from.

SAFETY OF PAINKILLERS LIKE OXYCODONE AND NOVOCAINE FOR ITP PATIENTS

Q **We've received questions about the safety of certain pain medications for ITP patients. One patient asked whether taking oxycodone for pain (for a fractured arm that will be in a sling 4 weeks) will have a negative effect of any sort on her platelet count or function. Her recent count was 65,000. A second patient asked if receiving Novocaine (or similar) anesthetic for dental work is safe for ITP patients.**

A We checked with our medical advisors and were informed that neither oxycodone nor Novocaine should have any significant effect on the patient's platelet number or function. However, if the oxycodone is administered with aspirin in the form of Percodan® then it could. Likewise, any injection (like Novocaine) in a patient with low platelets (especially into the oral cavity) could be risky if their platelets are below 30,000. The doctors would not be concerned about phlebotomy (giving blood for laboratory tests) or subcutaneous injections for vaccination. They might have to apply pressure a little longer than usual. To learn about effects of other drugs on platelets, visit our Warnings page at *http://pdsa.org/about-itp/warnings.html*.

SUBSTANCES THAT INTERFERE WITH PLATELET FUNCTION OR BLOOD CLOTTING

Q **With my low platelets (around 30,000) my bleeding time or likelihood of bleeding increases if I take ibuprofen or other anti-inflammatories. Thus, I stopped all anti-inflammatories several years ago. Are there other substances that would reduce my platelet function and increase my INR/PT (international normalized ratio/ prothrombin time) such as Tylenol® (acetaminophen), antihistamines, antacids, high Vitamin E dosage or other supplements?**

A Although the bleeding time is not a precise predictor of platelet function, any of the substances that interfere with platelet function can increase your risk of bleeding. In addition, the INR/PT are affected by medications such as warfarin (Coumadin®) and heparin, but not by anti-platelet agents. The INR/PT does not measure platelet function or predict bleeding in patients with low platelet counts. It measures the ability of the liquid (plasma) part of the blood

to clot. Problems with the liver, or use of the drug warfarin (Coumadin®), and a vitamin K deficiency can all increase the INR/PT and increase the risk for bleeding.

PDSA has on its website a list of various drugs, vitamins, supplements, and foods that affect platelet action. Visit: *pdsa.org/about-itp/warnings.html*.

ACQUIRING ITP BY BLOOD TRANSMISSION

Q **Can a person acquire ITP by sexual contact, including kissing? If a person has sexual contact with an ITP person with ITP antibodies in their blood, would that expose the person to those antibodies and a risk of getting ITP?**

A According to our medical advisors, the answer is "Absolutely no. Unless related to HIV, there is no transmissibility." ITP is not an infectious disease and it is not communicable. The viruses that can trigger a low platelet count may be passed to another person, but there is no guarantee an infected individual will develop ITP.

Resources

Whether you are newly diagnosed or have been living with ITP for years, PDSA can help you and your family through our comprehensive programs and services, including free online resources and booklets. You can access these resources by visiting *pdsa.org/booklets.* Our organization also publishes monthly e-news updates, a quarterly newsletter, and makes available other publications and articles on current information relating to ITP and other platelet disorders. Each year, PDSA holds an annual conference and regional meetings. PDSA has more than 66 local patient support groups in the U.S. and Canada and continues to expand its programs to offer more services and reach more people. For access to the most comprehensive information about ITP, consider becoming a PDSA Member so that many of our educational initiatives can be made available to you. You can learn more about becoming a member by visiting *pdsa.org/give-back/become-member*.

Our Natural History Study Registry collects valuable information to help improve the lives of those living with ITP. The ITP Natural History Study Registry is an international patient-consented registry of individuals with ITP and other platelet disorders. The registry aims to collect data on the natural progression of ITP and other platelet disorders, enabling PDSA to gather data on diagnosis and treatment, management of care, quality of life, and clinician reporting. The registry is administered by PDSA and overseen by NORD and a committee of leading hematologists, ITP patients and caregivers. Visit *pdsa.org/registry* and enroll today!

HELPFUL RESOURCES FOR MANAGING ITP

- Support Groups by region: *pdsa.org/support-groups*
- ITP Helpline: (440) 746-9003
- Medical Emergency Cards and Medical Alert Jewelry for Patients with ITP: pdsa.org/shop

Depending on your circumstance, one of our other booklets may also be helpful, and they can be found by visiting our webpage at pdsa.org/booklets. These booklets are available in multiple languages at *pdsa.org/translated-publications*.

- *ITP Pamphlet (perfect for sharing with families)*
- *For Women & Girls+ with ITP: Periods, Pregnancy, Menopause and More*

- *ITP in Adults – Frequently Asked Questions*
- *ITP In Teens – Frequently Asked Questions*
- *ITP in Children – Frequently Asked Questions*
- *Resource Guide for Parents of Children with ITP*
- *Coping with ITP – Frequently Asked Questions*
- *Understanding ITP – a story for kids with ITP*
- *The Role and Function of Platelets in ITP*
- *Health Insurance and Assistance Programs for ITP Patients*
- *Who Pays for Drugs in Canada?*

For more information about ITP, and other available resources, additional copies of this booklet, or to become a member of PDSA, please contact *pdsa@pdsa.org* or 440-746-9003.

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 a quarterly newsletter, discounts to the ITP Annual Conference, optional participation in the ITP POKE-R-Club, and Name Exchange Program.

PDSA would like to thank PDSA Medical Advisor Douglas Cines, MD, University of Pennsylvania, Philadelphia, PA for his review of the medical sections of this booklet. The information in this guide is for educational purposes only. For your unique medical condition, please seek the care of a qualified medical doctor and/or other health care provider.

PDSA is a 501(c)3 organization. All contributions are tax deductible. This patient information guide is supported by an educational donation provided by Sanofi. The information in this guide is for educational purposes only. For your unique medical condition, please consult a physician.

USE THIS FORM TO:

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- JOIN PDSA
- REQUEST FUNDRAISING INFORMATION

Please check the appropriate box(es).

All donations to PDSA are gratefully received and will be acknowledged.

(Please make checks payable to: PDSA) (Do not send cash)

☐ 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.

☐ I enclose a donation to PDSA of: $_____.

☐ 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 website: *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: (440) 746-9003.

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

Platelet
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Support
Association

Empowering ITP Patients

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