

ITP in Adults

FREQUENTLY ASKED QUESTIONS



Platelet
Disorder
Support
Association

Empowering ITP Patients



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Q What is ITP?

A Primary immune thrombocytopenia (ITP), is a rare hematological autoimmune disorder where the body mounts an immune response towards platelets and destroys them. The cells in the bone marrow that make platelets may be targeted as well. As a result, adults with ITP have low platelet counts. ITP is characterized by isolated thrombocytopenia with a blood platelet count of less than 100,000 per microlitre (μl) of blood with normal being greater than 150,000. ITP affects 3.3 per 100,000 adults each year over the age of 18 years, many over the age of 60 years.

Approximately 20% of all diagnoses of immune thrombocytopenia (ITP) is secondary to an underlying medical condition that is associated with the immune destruction. Disorders that may be associated with immune thrombocytopenia include lymphoproliferative conditions, other autoimmune disorders such as lupus and rheumatoid arthritis, infections, and certain hereditary conditions including a primary immunodeficiency. Some drugs can also cause a low platelet count by an immune or non-immune mechanism. Understanding if your ITP is primary or secondary can be important to ensure appropriate health care follow-up and correct treatment management. Distinguishing between primary and secondary ITP is not always possible at the time of diagnosis but should always be considered since primary ITP is a diagnosis of exclusion and appropriate treatment may depend on treating the underlying condition.



Q What are platelets?

A Platelets are small, sticky components of our blood formed in the bone marrow (the soft, porous tissue found in the bones of the body). They can only be viewed under a microscope. They are required to maintain the integrity of our blood vessel walls and seal cuts and wounds by initiating the formation of a blood clot. Without a sufficient number of platelets, clotting isn't as successful, can take longer, and can sometimes lead to spontaneous bleeding or bruising or bleeding with minimal injury.

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

— GREG

Q What is a normal platelet count?

A Normal platelet counts range from 150,000 to 400,000. Having a platelet count between 100,000 to 150,000 means you have a lower than normal platelet count, however it is generally not associated with any increase in bleeding tendency and does not necessarily mean you have ITP. Although individuals with a platelet count less than 10,000 are more prone to bleed, symptoms are quite variable between individuals with ITP and even below this count many patients with ITP will not experience significant bleeding symptoms. Treatment is encouraged for adults when the platelet count falls below 20,000 even if bleeding symptoms are not present. Spontaneous bleeding is more common in adults with a platelet count less than 30,000.



Q What causes ITP?

A The specific cause of ITP is unknown. It may appear following a viral or bacterial infection in healthy adults. It is thought that this infection causes the immune system to lose the ability to distinguish between the body's own cells and those of invaders, like bacteria. As a result, the immune system targets the body's own platelets. Why ITP occurs in some adults and not others who may have been exposed to the same viral or bacterial infection is not known. Some individuals with a family history of autoimmune disease may be more likely to develop ITP and some individuals with inherited immune deficiencies are at higher risk of having ITP. It is important to recall what was happening in your life before you began having symptoms of low platelets, including any exposures to new drugs, herbs or supplements. This information may be useful to your physician in diagnosing and treating your low platelet count.

Q What are the symptoms of ITP?

A The symptoms vary greatly from person to person. Some adults do not have any symptoms despite a low platelet count. 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 on the skin is caused by broken blood vessels or leaks in a capillary wall. Some adults will experience more involved bleeding. Signs of serious bleeding risk include heavy mucosal bleeding in the mouth, gastrointestinal system, urinary tract, nose and brain. Women may also experience heavy bleeding (menorrhagia) and prolonged menstruation with their periods.

Fatigue is a common experience for many people with ITP. It may be caused by the disease, or it could be a response to treatment. The underlying cause of fatigue in ITP isn't clear but is very real. Many people with ITP also report feeling depressed. While the exact underlying mechanism for this is not clear, several explanations have been proposed, including that serotonin, a neurotransmitter that is carried by platelets and delivered to the brain and other parts of the body and helps regulate mood. Dealing with a difficult and potentially chronic illness can lead to feelings of isolation, fear, and anger that your body has "turned against you." A third factor could be the treatments. Many of them



list depression as a potential side effect. Aches and pains may also be part of ITP. We are learning more about both the mental and physical consequence of ITP each day, in part because of our ITP Natural History Study Registry. If you would like to share your experience with ITP for the greater good, please visit itpstudy.iamrare.org or pdsa.org/healthcare-professionals-researchers/hcp-registry.

Q How is ITP diagnosed?

A ITP is a diagnosis of exclusion. This means, there is no accurate, definitive test for ITP. Your doctor will order a test called a complete blood count test (CBC) to measure features in your blood, including your platelets. The diagnosis is confirmed when platelets are less than 100,000 per microlitre in the absence of any obvious underlying secondary cause. Your physician may order other testing to rule out an underlying cause of low platelets depending on your symptoms, family history, physical exam, and other blood counts.

It can be difficult to rule out underlying causes at the time someone is diagnosed with ITP. After ruling out artificial lab results such as pseudothrombocytopenia (most common etiology is platelet clumping in the test tube only), a physical examination can provide diagnostic clues if the spleen or liver are enlarged for example or if large lymph nodes are present. It is also essential that your physician examine your platelets under a microscope and order additional testing if the platelets are not the expected size or appearance, or if other blood cells look abnormal.

Q What is a “bone marrow aspiration or bone marrow biopsy” test and why is it performed?

A Bone marrow examinations are not necessary for the majority of ITP patients. They are generally not used to make a diagnosis of ITP. In some cases, a hematologist (blood specialist) will ask to take a sample of bone marrow from the pelvic bone (bone marrow test), if there is no response or a loss of response to common ITP treatments, or if there are other abnormal findings in the blood or physical exam that suggest a disorder underlying the ITP. This is performed to ensure that the bone marrow is still making platelets and that there is nothing wrong with the other blood cells in the marrow. Pain medication is provided to make the experience more comfortable.



Q Will I recover?

A Approximately 20% of adults who develop ITP will recover quickly following their diagnosis. An additional 10-20% may recover over time, usually with some treatment. It is important to understand there are three phases of ITP. The likelihood of recovery depends on age and what phase your ITP falls into. The phases include:

- Newly diagnosed ITP: Within 3 months from diagnosis. Most cases (80%) of adult ITP will not resolve within this time whether they receive treatment or not.
- Persistent ITP: 3-12 months from diagnosis without resolve (or remission).
- Chronic ITP: Lasting more than 12 months from diagnosis.

While very young children and some teens are more likely to see their ITP spontaneously resolve, other adolescents and adults are more likely to have a chronic course. Recovery is possible even if you are considered to have chronic ITP.

Q Is ITP life-threatening?

A The potential danger with ITP is primarily related to a risk of bleeding. Life-threatening bleeding is very rare. If you have already experienced bleeding more involved than just spontaneous bruising or petechia you are at a higher risk for more serious bleeding. However, the risk for having an intracranial hemorrhage, for instance, remains extremely low. The risk for an adult to experience a spontaneous intracranial bleed (unrelated to injury) as a direct consequence of their low platelet count is approximately 1.5%. This risk may be higher if you've already experienced serious bleeding episodes that required immediate hospitalization and treatment, or if you've had a head injury while your platelet count is low, particularly under 30,000. A very small percentage of people with ITP die from the disease or the treatments. The large majority of people find treatments that raise their platelet counts to a safe level or successfully live with a low platelet count.

Injuries to the head should be reported to your physician immediately. *Especially if over the next day you experience a persistent or fluctuating headache with or without fatigue, nausea, vomiting, or a low-grade fever. These may be signs you are having an intracranial bleed. Bleeding with ITP is often slow, with time to intervene, if you know about the bleed. Therefore, it is important to report all injuries to your physician when your platelet count is low, especially injuries to the head even if mild. They may recommend physician examination or a CT scan of the head.*

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

— ROSELLYN

Q When should I seek immediate medical attention?

A Seek medical attention immediately if you experience any of the following:

- A change in bleeding and/or bruising pattern.
- A nosebleed that cannot be stopped.
- A headache (spontaneously or due to injury) of any degree that is worsening, persistent, or keeps returning. Especially in the presence of excessive fatigue, poor/no appetite, vomiting, and fever. These may be the signs of an intracranial bleed.
- Following any head injury/trauma. Especially if you feel stunned and/or show signs of unusual behavior. Often brain bleeds start out as a slow bleed with time to intervene (if you are aware there is a bleed) and may not reveal traditional symptoms right away.
- Obvious blood in the urine. This is called gross hematuria and may be a future predictor for more serious bleeds.
- Black dark stool, bright red blood when going to the bathroom and/or vomit that resembles coffee grounds. Especially if your abdomen feels distended (swollen). These are signs of a gastrointestinal bleed.
- An injury that shows signs of significant swelling.

It is very important that in an emergency situation medical staff are quickly made aware of your ITP diagnosis. *PDSA has a variety of medical awareness jewelry available for purchase through the Platelet Store: pdsa.org/products-a-publications/the-platelet-store.*



Q **If I have ITP will my children have ITP? Should I be concerned other family members could develop ITP?**

A ITP is not considered a hereditary disorder. Since ITP is a diagnosis of exclusion and underlying (often hereditary) causes are not routinely investigated, as many as 1 in 7 individuals with a diagnosis of ITP are misdiagnosed. If ITP does run in your family, it would be important for you to talk to your physician about considering a referral to a genetics clinic to discuss the option of appropriate molecular based genetic testing to help identify why ITP is present in multiple family members, as that is not typical. If your ITP is due to an underlying hereditary thrombocytopenia but is diagnosed as ITP, then the risk to have a child with ITP could be as high as 50%. Inherited causes of ITP are not common.

Q **Is ITP contagious?**

A No, ITP is not a contagious disease.

Q **Am I at risk to develop other illnesses because I have ITP?**

A If you are otherwise healthy, you are no more susceptible to contracting other illness or viruses than others who do not have ITP. However, if you are receiving corticosteroids or other drugs that suppress your immune system as part of your ITP treatment, or you've had a splenectomy, your ability to fight off infections will be reduced. Some individuals have reported developing more than one autoimmune disorder in addition to their ITP. The science behind this clustering effect is not yet well understood but could in part be due to genetic factors.

Q **Can ITP be cured?**

A There is no cure for ITP. Fortunately, most adults with ITP do not experience serious bleeding, and many have platelet counts above 30,000 per microlitre. Some patients have a platelet count lower than this and require treatment for bleeding prevention. Many patients find their platelet count improves following treatment. What proves difficult for many ITP patients is finding the treatment that works for them with minimal side effects. Some patients report that

changing their diet or lifestyle helps them feel better. ITP can go into remission for a long time, perhaps for the remainder of a person's life. ITP can also recur. A recurrence of ITP may indicate chronic ITP or secondary ITP and should be monitored carefully. Consult your physician for further information. Currently, there is no way to predict the course of the disease.

Q Are there medications I should avoid taking?

A It is important to note that adults with ITP should not take any medication that contains acetylsalicylic acid (such as aspirin), anti-inflammatory medications containing ibuprofen (such as Advil® and Motrin®) or naproxen (such as Aleve® and Midol®). Adults with ITP should also avoid medicines containing glycerol guaiacolate (such as Robitussin® and Mucinex®) since these medicines can prevent the limited number of platelets from working properly. Anticoagulants such as warfarin, heparin, apixaban or other similar drugs can significantly increase the risk of bleeding. As a precaution, check with your physician before taking any medicine, vitamin, or supplement other than acetaminophen (Tylenol®). It may also be helpful to avoid alcohol since it can suppress the bone marrow.

Many families wonder about alternative or complementary therapies, such as herbs, special diets, supplements, and non-traditional medicine. It is important if you are pursuing one of these therapies to let your physician know since many complementary 'natural' therapies can negatively interact with other more traditional therapies which could lessen their effectiveness or in some cases be harmful to you in combination. High doses of some supplements, such as turmeric or garlic can increase the risk of bleeding. Please visit the PDSA website pages on "Outside Influences" and "Complementary Therapies" using this link: pdsa.org/treating-itp.

Q Are there treatment guidelines?

A Yes. The two main statement reports include the American Society of Hematology (ASH) clinical practice guidelines and the International Consensus Report (ICR) on ITP management. Both were updated in 2019 and can be viewed by visiting pdsa.org/healthcare-professionals-researchers/hcp-resources.

Q When should I be treated?

A The decision to start treatment is one that both you and your physician should make together based on recommended professional guidelines, platelet count, disease phase, bleeding history, lifestyle, and overall health-related quality of life (HRQoL) for both the ITP patient and their family.

In terms of treating according to disease phase, professional guidelines (2019) recommend:

Newly Diagnosed:

- Unless your platelet count is very low (under 20,000-30,000) or you've already experienced a bleeding event beyond mild skin manifestations (such as bruising and petechia) it is very likely your physician may suggest you follow a "Watchful Waiting" management approach. With this approach, you would be followed closely with frequent check-ins in place of treatment with drugs. This is an active management approach that ensures you will not be over treated with drugs that have significant side effects when your ITP may resolve quickly, and you may never have a serious bleeding event. While there is no established 'safe' platelet level since it's different for everyone based on their activity levels, previous bleeding history, and other symptoms.
- "Watchful Waiting" is not appropriate for adults with ITP who have very low platelet counts or have bleeding symptoms, or develop bleeding symptoms, beyond typical bruising and/or petechia.
- Recommended treatment is usually a short dose of corticosteroids, such as prednisone.
- For very low platelet counts with or without bleeding intravenous gamma globulin (IVIG) may be given.

Persistent ITP:

- Similar to when newly diagnosed, treatment is reserved for those with bleeding beyond petechia and bruising, and for those who have a platelet count below 20,000-30,000 or require a medical procedure such as surgery. Treatment with TPO-RA's are recommended at this phase, particularly if you cannot safely reduce your steroid dose.

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

— DEBRA



Chronic ITP:

- Treatment with TPO-RA's are recommended over steroids. TPO-RA's are recommended over Rituximab, and both TPO-RA's and Rituximab are recommended over splenectomy which should be considered only after consideration of other treatments have been considered. Management should be focused on optimizing health related quality of life (HRQoL) while reducing the risk for bleeding.

It is important to have a plan in place for a bleeding emergency. It is also important for adult patients to report to their physician during each visit any new bleeding symptoms you may be experiencing. When new bleeding symptoms appear, a change in management may be appropriate.

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

— WAYNE

Q What treatments are available?

A There are many treatments for ITP. They all have different risks and benefits, and some are very toxic. It is important to understand both the success rate and potential side effects before beginning any treatment. Hematologists may use a combination of treatments at once to increase their success rate. Side effects have been reported for each drug used to treat ITP. However, side effects vary and may not be experienced by everyone taking the same drug. For more information on specific treatments available, please see pdsa.org/conventional.

If you are a woman with ITP and you become pregnant, some of the anti-platelet antibodies may cross the placenta and your baby may temporarily develop low counts. If this happens, after birth the baby may be treated to prevent bleeding. When the baby's own immune system matures, the platelet count improves but this can take weeks to months. If you are a woman with ITP and are not yet pregnant, but are planning a pregnancy, it is recommended to talk to your physician for additional information. International Consensus guidelines recommend treating pregnant women when their platelets are under 20,000 regardless of bleeding symptoms, but that counts between 20,000-30,000 are felt to be safe in the absence of bleeding and/or required procedures. A platelet count of over 50,000 is recommended for a safe delivery. Corticosteroids are recommended to be used first when treatment is indicated in a pregnant woman with ITP. Several treatments for ITP are safe for both mother and fetus, but both your obstetrician and hematologist should discuss with you risks before beginning them.



An epidural can be used during labor. The recommendation for safe placement of the epidural catheter is a platelet count of at least 70,000. A spinal injection for anesthesia requires a platelet count of at least 50,000. A plan to raise the platelet count prior to delivery should be discussed with your physicians early in your pregnancy. For more information on ITP and Pregnancy, see pdsa.org/images/stories/pdf/ITP-Female-2015.pdf.

Q Can I still do the things I love?

A This is an individual decision based on your platelet count, your symptoms, your current lifestyle and the amount of risk with which you are comfortable. Your physician should provide some guidance for you. Some people with ITP find new activities to enjoy that do not place them at risk of bleeding. It is important to find a way to live with your ITP (your “new normal”) that makes you feel empowered and safe, while still enjoying your life. ITP has been shown to impact an individual’s overall quality of life, so the more you focus on what you can do instead of what you cannot do, the better your experience with ITP will be.

Physical activity is important, however if the platelet count is low, certain activities may need to be restricted in order to lower the risk of bleeding. As long as your platelet count is over 75,000 it is usually safe to play sports using protective equipment. There are some sports that are considered dangerous for anyone even without a bleeding disorder. Deciding on what sports you can participate in will depend on the degree of risk association with it.

Q Am I eligible to go on disability?

A Some people with ITP have been successful in obtaining disability assistance. Others have found it a challenge. The severity of this disease and the impact on lifestyle varies greatly. Your success in getting disability assistance depends on how your case is presented and on the specific difficulties you are experiencing as a result of the ITP. If you are living in the US, contact the Social Security Administration for more information. If you are living in other parts of the world, talk to your physician about who you should contact to assess your disability claim. See “Assistance Programs” for additional resources at pdsa.org/patients-caregivers/support-resources.



Q What should I tell my family, friends, and my employer?

A What you tell people about your ITP diagnosis will likely depend on their role in your life, and how comfortable you are with sharing your private information. Below is a guide you can use that will help you communicate your ITP diagnosis with those you want to disclose this to.

For acquaintances, you may want to say:

“ITP is a blood clotting disorder. I bruise and bleed very easily. But it’s not contagious.”

For friends and family, you may want to say:

“ITP is a rare autoimmune bleeding disorder. It is not hereditary. I need to be cautious because I can bleed and bruise with very minimal injury due to the fact my platelet count is low.”

For employers you may want to say:

“ITP puts me at risk of bleeding with minimal injury. If I am bleeding, this is how to stop it, and this is how to reach my emergency contact. If trauma occurs such as a loss of consciousness, call 911 immediately, then my emergency contact and my physician listed on my emergency protocol I’ve provided you with.”

If you are on medication, you may want to consider adding:

“The medicine makes me feel hungry/tired/irritable.”

Please feel free to distribute this booklet among caregivers, friends and family members. The information it contains will not only increase their understanding of ITP but may also minimize their fear and anxiety.

Q What can family and friends do to help?

A Most people are quite shocked to receive this diagnosis. They probably have not heard of ITP before being diagnosed and have no idea what to expect. First reactions may include fear, confusion and stress. It’s difficult to assimilate all the new terms and understand the treatment options in a crisis situation. You can ask your family and friends to be extra patient. You can explain that you have a lot on your mind. You are learning as fast as possible and if you are on a treatment, you are dealing with the side effects of some very potent drugs. You can explain that sometimes you may feel awful, tired and sad.



Although you may look just fine, your body is adjusting to living with an autoimmune disorder.

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

A You should learn as much as you can about the disease. Learn the benefits and the side effects of the recommended medications, decide how you want to approach the disease and your life, now that it has changed. Keep a copy of every lab report and copies of all blood work. Maintain a log of the medications used, dosages, your platelet count, and how they made you feel. Pay attention to your lifestyle and see if there is any correlation between your platelet count and the food you eat, stress level, the places you visit, toxins in your environment, etc. Often you are the person paying the most attention to these things, and you know your body better than anyone else. Be proactive in your diagnosis by staying on top of the guidelines and current information. To help you do this, visit us at pdsa.org.

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

— BARBARA

Q Where can I get more information?

A The Platelet Disorder Support Association (PDSA) supplies information about ITP applicable to all patients, whether newly diagnosed or living with ITP for years, and their caregivers through our comprehensive website including free online resources and booklets. You can access these resources by visiting pdsa.org. Our organization also publishes a monthly e-news update, a quarterly newsletter and makes available other publications and articles. Each year, PDSA holds an annual conference and regional meetings. PDSA has more than 60 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.

PDSA also offers several ways to connect with other adults living with ITP. These include private discussion groups on the PDSA website and our social media channels, a name exchange program, an annual patient conference with adult ITP sessions, regional meetings during the year, and virtual ITP Support Group meetings. PDSA's global ITP



National History Study Registry connects patients with research opportunities where you can join thousands of patients living with ITP from around the world to advance research and improve the quality of life for ITP patients. Visit pdsa.org/registry and enroll today!

Thank you to PDSA Medical Advisor Terry Gernsheimer, MD, for her valuable assistance and contribution of information for this free educational booklet.



Resources

HELPFUL RESOURCES FOR ADULTS MANAGING ITP:

Support Groups by region: pdsa.org/support-groups

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

Online Discussion Groups: pdsa.org/discussion-group

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)

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

Coping with ITP – Frequently Asked Questions

Living with ITP – Answers to Common Questions

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 us:

Platelet Disorder Support Association

8751 Brecksville Road, Suite 150, Cleveland, OH 44141
(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 a quarterly newsletter, discounts to the ITP Annual Conference, optional participation in the ITP Poke-R-Club and Name Exchange Program, and the good feeling of helping others.

PDSA is a 501(c)3 organization. All contributions are tax deductible. This patient information guide is supported by an educational donation provided by **argenx**.

The information in this guide is for educational purposes only. For your unique medical condition, please consult a physician. The names of actual companies and products mentioned herein may be the trademarks of their respective owners.

Use this form to:

- MAKE A DONATION TO PDSA
 - 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

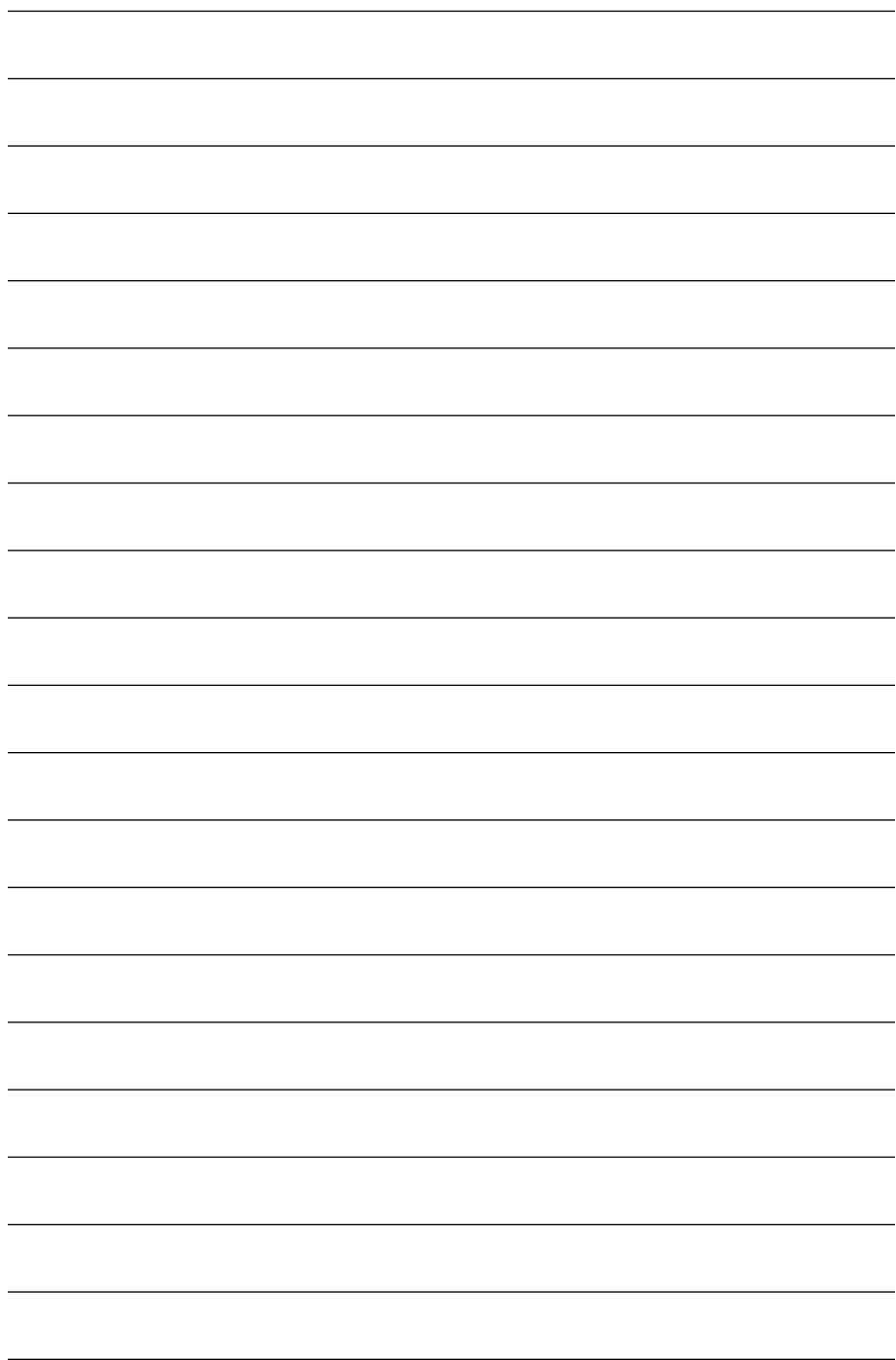
For additional information about ITP and PDSA visit our website:
www.pdsa.org or send email to pdsa@pdsa.org

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:
(440) 746-9003

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







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