GUIDE TO

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Living with ITP

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Expert treatment and a positive attitude help Barbara Pruitt stay active and have fun

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Platelet Disorder Support Association

Empowering ITP Patients

GUIDE TO

Living with ITP

10 Barbara Pruitt, here with husband Peter, enjoys an active life, including the occasional nine holes—and ITP doesn't get in the way.

The basics

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True inspiration

18 Bob Monigle and Trish Beattie Santaromana share their best tips for thriving with ITP.

Feel your best

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Platelet Disorder Support Association
Empowering ITP Patients

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RPA20

COVER PHOTO BY TOLGA KAVUT

Here's to more *joy* ahead!

Today's treatments for immune thrombocytopenia (ITP) bring remission within reach—and free you to enjoy work, play, friends and family.

Last fall, Ingrid P. went on a trip to Ireland with her husband—and marked a milestone. "I hadn't flown anywhere in years because I hated worrying about my chronic ITP when I was far from home. I worried that my platelets would crash and I'd somehow cut myself and bleed uncontrollably!"

In fact, Ingrid had resigned herself to "stay-cations" because she found traveling *anywhere* stressful. "My husband wasn't happy about staying home during his time off," she says. "I felt bad that my ITP was affecting his freedom, too."

But soon, Ingrid had a reason to tackle the problem head on. Her sister, Lily, who lives in Dublin, was getting married, and Ingrid was determined to be there for the wedding.

Her first step? Talking with her hematologist and having a frank discussion about her frustration with her current treatment. "I had started to question whether this was truly the way life had to be—chronic low platelets, petechiae [red or purple dots on the skin], purpura [bruises] and nosebleeds that messed up more days than I'd like to remember!"

Luckily, Ingrid's doctor prescribed a different therapy for her ITP. "I take a pill once a day—anytime during the day," says Ingrid. "It couldn't be easier—and it works! A few weeks after I started it, my counts were back up—and they've stayed there! I stopped worrying so much about 'what might happen,' booked our flights and started shopping for a dress for the wedding! Knowing my platelets would stay in a healthy range—I finally felt hopeful!"

What about you?

A rare disease, ITP affects about 9.5 out of every 100,000 Americans. If, like Ingrid, you're a member of that group, you, too, can take back control. The best approach: Work with your hematologist to find the treatment that can boost your platelets and help you live your life to the fullest—and with confidence!

DID YOU KNOW?
About 9.5 out of every 100,000 Americans are affected by ITP. Get the info you need to stay ahead of this condition right in this guide.

ITP: What you need to know

Yes, you can reduce the risk of serious problems caused by low platelet levels due to ITP—and your care team will be with you every step of the way!

Immune thrombocytopenia (ITP) is a rare condition marked by a low number of platelets in your body. Platelets are blood cells produced in the bone marrow, the soft, spongy tissue in the center of large bones. They bind together to form clots, which prevent your body from bleeding excessively. In ITP, the body perceives one's own platelets as foreign and produces antibodies that accelerate their removal from the blood, thereby increasing the risk of bleeding.

According to the National Heart, Lung, and Blood Institute, normal levels range from 150,000 to 450,000 platelets/microliter of blood in most laboratories. But for people with ITP, platelet levels fall below 150,000—and sometimes dangerously low. At very low platelet counts, the risk of bleeding goes up. In severe cases, this can be life threatening. ITP is considered "persistent" when it lasts from 3 to 12 months, and "chronic" when it lasts for more than a year.

Who is at risk for ITP?

According to the Platelet Disorder Support Association (PDSA), the most recent data published reports that the number of people who are diagnosed with ITP each year is 3.3 per 100,000 adults. The *prevalence* of ITP in adults—i.e., those who have ITP at any time—is approximately 9.5 cases per 100,000.

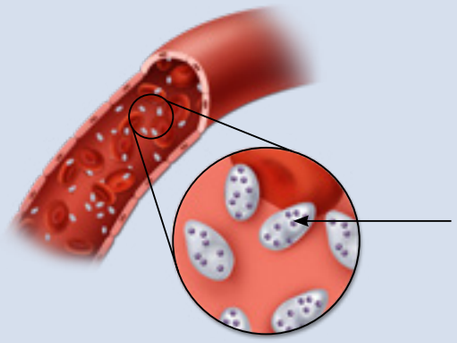
ITP can strike people at any age and affects more women than men ages 30 to 60. Yet, research shows men are equally affected in other age groups.

It's also good to note that ITP does not appear to be genetic, so a family member having it doesn't necessarily raise your risk.

How platelet levels drop

Low platelet levels occur when:

- The immune system malfunctions and perceives platelets as enemies, creating antibodies that attach to the platelets and destroy them.
- The spleen holds on to too many platelets. Normally, the spleen stores about a third of the body's platelets, and also helps flush out old ones. When platelets are coated with antibodies, the body may remove them from the blood and trap them in the spleen to be stored or flushed.
- Your bone marrow doesn't make enough platelets. A protein made in the liver called thrombopoietin (TPO) stimulates bone marrow cells to make platelets. The antibodies in those with ITP may impair the response of cells that make platelets. If not enough TPO reaches the bone marrow, not enough platelets are produced to replace the platelets that have been destroyed.

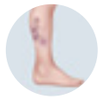


Platelets are the disc-shaped blood cells that help your body form clots.

The symptoms of ITP

ITP symptoms can vary from person to person, and may include:

Tiny red or purple dots on the skin (petechiae)



Excessive bruising (purpura)

Bleeding too easily from the gums, nose or cuts

Bleeding that's hard to stop

Symptoms may also include: heavy menstrual bleeding and blood in urine or stool. Many people with ITP complain of low energy levels.

How is ITP diagnosed?

Your doctor will take your medical history to help rule out any other potential causes of your symptoms, such as certain medications, infections or other medical conditions. They will also perform a physical exam and order a complete blood count (CBC), a blood test that shows the number of platelets and other blood cells, as well as a blood smear, in which blood is viewed under a microscope. Other blood tests may be needed to exclude certain infections and other causes of thrombocytopenia. In rare cases, a bone marrow exam is required. In this exam, a sample of the liquid portion of the marrow is obtained using a hollow needle inserted into the bone and marrow (aspiration) and a sample of the bone tissue and the enclosed marrow is removed using a larger needle (biopsy).

Treatment can help!

Today's treatment options mean ITP can be effectively treated. But, be patient. You may need to try more than one treatment before you find the one that keeps your platelet levels at a healthy place for you. Keep reading this guide to learn about the treatment options and lifestyle steps that are helping people with ITP fend off complications and say yes to all the things they love.

Your ITP care team

There's no reason to struggle with ITP alone! These are the medical pros who can help you manage the condition.

- **Primary care provider (PCP):** This medical professional can help coordinate your overall medical care and refer you to specialists.
- **Hematologist:** This doctor specializes in conditions relating to the blood. ITP is not a cancer, but some hematologists are also oncologists, specializing in cancers of the blood.
- **Social worker/ therapist:** This healthcare professional can help you work on coping strategies for the stress and emotional challenges that may accompany ITP.
- **Nurse:** This licensed healthcare professional provides and coordinates patient care.
- **Nurse practitioner/ physician assistant:** This specially trained healthcare professional will often work closely with your doctor to create your treatment plan.

Take charge of ITP!

The right treatment can help you enjoy life—without worrying about dangerous platelet levels!

Here's the good news: Your dreams of freedom—from the worry of crashing platelet counts, spontaneous bruises and bleeds, and the frustration of being held back by immune thrombocytopenia (ITP)—are within reach. Although there is no cure for ITP, the right treatment can help you manage your ITP and live life to the fullest. The key to unlocking that potential? Working closely with your doctor toward a common treatment goal: remission. The treatment that's right for you can help keep your platelets at a level that lowers your risk of bleeding incidents—potentially for the rest of your life!

Be persistent!

If your ITP is mild, you may only need to get regular platelet checks so your doctor can monitor you. But if you do need treatment, you have many options to consider. Together with your doctor, you may decide on a single treatment or a combination of treatments to maintain your platelets at a level that gives you the quality of life you desire. You may also rely on other treatments to boost your platelets quickly if they drop dangerously low.

Important to know: The severity of ITP and the responses to treatment vary, so there's no one-size-fits-all solution. And because the disease can change over time, you may need to try different treatments to find the one that works best for you. So, be patient! And don't be discouraged if the therapies you've tried have not been effective—with so many options available, there's every hope that one of them will be your key to remission.

Which medication for *me?*

Your choice of which medication to use depends on many factors, which is why you should never hold back when talking with your healthcare provider. Knowing how you're feeling, how ITP affects your daily life and the type of treatment you prefer—for example, a pill every day rather than periodic injection or infusion—will help your doctor determine which therapy to try. Also, never skip a blood test, as your doctor uses the results to assess how well your treatment is working and how to adjust your dosage. Current options include the following:

- **Corticosteroids,** including prednisone and dexamethasone, decrease the immune system activity that destroys platelets. Corticosteroids are often the first ITP therapy your doctor prescribes because they are oral and have a high response rate, but are also used as emergency treatment, given in the hospital by IV, if your platelets fall dangerously low. Even if your platelet count responds, it is important to consider other treatments to minimize your exposure to corticosteroids.
- **Platelet growth factors,** such as avatrombopag (pill), eltrombopag (pill) and romiplostim (weekly injection), are also referred to as thrombopoietin receptor agonists (TPO-receptor agonists). They increase platelets by stimulating your bone marrow to produce more platelets, but do not affect the rate of platelet destruction. They may be recommended after a first relapse while on steroids.
- **Immunosuppressants,** such as rituximab, given by infusion, also suppress the production of antibodies that destroy platelets.
- **Immunoglobulins (IVIG),** given by infusion, help to quickly increase your platelet count and may be used as emergency treatment.
- **Fostamatinib,** which impedes platelet clearance, has recently been approved and is another alternative.

Other treatment options

- **Platelet transfusion** may be administered if you are hospitalized with bleeding and very low platelets. Donor platelets from a blood bank are used to boost your supply of platelets temporarily.
- **Splenectomy** is surgery to remove the spleen, the organ that traps platelets and destroys them. By removing the spleen, more platelets remain in the blood. This surgery is effective in over 60% of ITP patients but may raise your risk for infection and blood clots.
- **Other medications** are available, and drugs may also be used in combination, if necessary.

Do *your* part

To manage your ITP so you can live your life with confidence, work closely with your doctor and follow your treatment plan to the letter. Monitor your progress and get blood work on schedule, per your doctor's instructions. And talk about your symptoms and any side effects you're having—it can help your doctor understand if your treatment needs to be adjusted. Talking frankly about how you're doing and discussing your preferences—i.e., pill or injection—with your doctor will help you find the therapy that's right for you. Best of all, it will give you the confidence to enjoy your favorite activities without worry.

Beating ITP with a platelet growth factor

Most ITP treatments work by preventing platelets from being destroyed or lowering antibody production. But many people with ITP have trouble producing sufficient numbers of platelets, which can partially account for their low platelet levels. Platelet growth factors, otherwise known as TPO-receptor agonists, boost the production of platelets by stimulating cells in the bone marrow that manufacture them. How do you know if you might benefit from this type of treatment? If you've been on treatment and you still have low platelet counts, a platelet growth factor medication may help boost your counts and even enable you to stop other ITP medications, such as corticosteroids or IVIG. In some cases, long-term treatment with a platelet growth factor may be necessary.

"I choose *cheerful!*"

Barbara Pruitt says self-care, a great hematologist and support from family, friends and the ITP community help her live fully! —BY KATHLEEN ENGEL

After nearly six decades of having ITP, Barbara Pruitt has had her share of setbacks—but low platelet counts have never brought her down and held her there, says the 62-year-old from Coral Gables, FL. "My family has always had a boat, so water has been part of our life: boating, fishing, swimming, snorkeling." Her easel is always set up for when she has the urge to paint; she plays Mahjong every week, regularly golfs nine holes and takes water aerobics classes. Several times a day, Barbara takes her dogs out for walks. And twice a week, she and her husband, Peter, baby-sit their two grandsons, Jack, 8 months, and William, 22 months; on one of those days, Barbara puts Jack into a stroller and walks a little under a mile to his music class at the University of Miami. And when ITP fatigue is too great, she rests. "My mantra has been 'Rest to Rally,' " she explains. "If there is something I really want to do, I make sure I get enough rest prior to it so I can have the energy to enjoy myself. I don't let ITP stop me from doing things and enjoying life!"

"A positive attitude is key!"

Barbara was only four when her mom took her to the pediatrician to investigate the bruises covering her body. He referred Barbara to a specialist, who diagnosed her with ITP. "I haven't known life without ITP," she says.

For a time, Barbara took steroids—but discontinued them when she was unable to sleep at night (and also because they did not boost her platelet counts). At age 7, she had surgery to remove her spleen, the organ that removes platelets from the blood, which put her in remission for three months. She has tried different treatments since then, including a long-term platelet booster, to help keep platelet levels in a healthy range. "I've always thought, when a new treatment becomes available, *Let's try it!* I go into it with a hopeful, positive attitude."

"Love and support have gotten me through!"

"My parents were terrific," says Barbara. "They kept me busy—enrolling me in activities like Girl Scouts, dancing and choir. I didn't grow up feeling 'different' or like I was missing out on things." Her doctors over the years also encouraged her not to stress about ITP. One, she recalls, counseled her and her husband when they got engaged. "He said, 'You guys are in love. Enjoy life and have fun.' I loved that attitude! I've never wanted to feel like a victim [of ITP]."

These days, Barbara lets her doctor know when she needs to see him—so her appointment schedule is on her. "He asks, 'When do you want to come back?' Sometimes it's in six months. Sometimes it's in two. He knows I'm careful and he trusts me—which is a really nice relationship to have. He knows that if I do call—for example, if I notice an increase in my bruising, if the petechiae have gotten worse and especially if I have blood blisters in my mouth—I need to see him right away and he gets me in." She gets her platelets checked at her appointments.

"ITP helped me find my purpose!"

"I was 40 before I met anyone else with ITP," says Barbara. "I was elated! I had flown to my first PDSA [Platelet Disorder Support Association] conference—which is the best thing you can do for yourself as a patient. You automatically have a room full of kindred spirits. They've walked down the road you've walked on. They know how you feel. As much as your friends and family love and support you, they don't know what it's like to walk in your shoes. When you go to a conference and meet others who have, there's a connection that cannot be matched. It's empowering! And you get access to the brilliant medical minds who are doing the most current research on ITP—you can ask questions you maybe haven't asked your own doctor!"

Fifteen years ago, "I decided it was time to be an ITP advocate and not just a patient," she says. She has since traveled across the country to share her story, describe her challenges and offer input, including with the FDA's hematology group and again at the American Society of Hematology (ASH) as they updated the society's 2019 treatment guidelines. And on any given day she might speak with someone who reaches out to the PDSA. "They have my phone and email. I told them I'm available to talk to any patient who calls and wants to talk to another patient. This week, I talked to a person I hadn't spoken to in years!" says Barbara. "It's a good feeling to know there's someone else out there who knows what you're going through!"

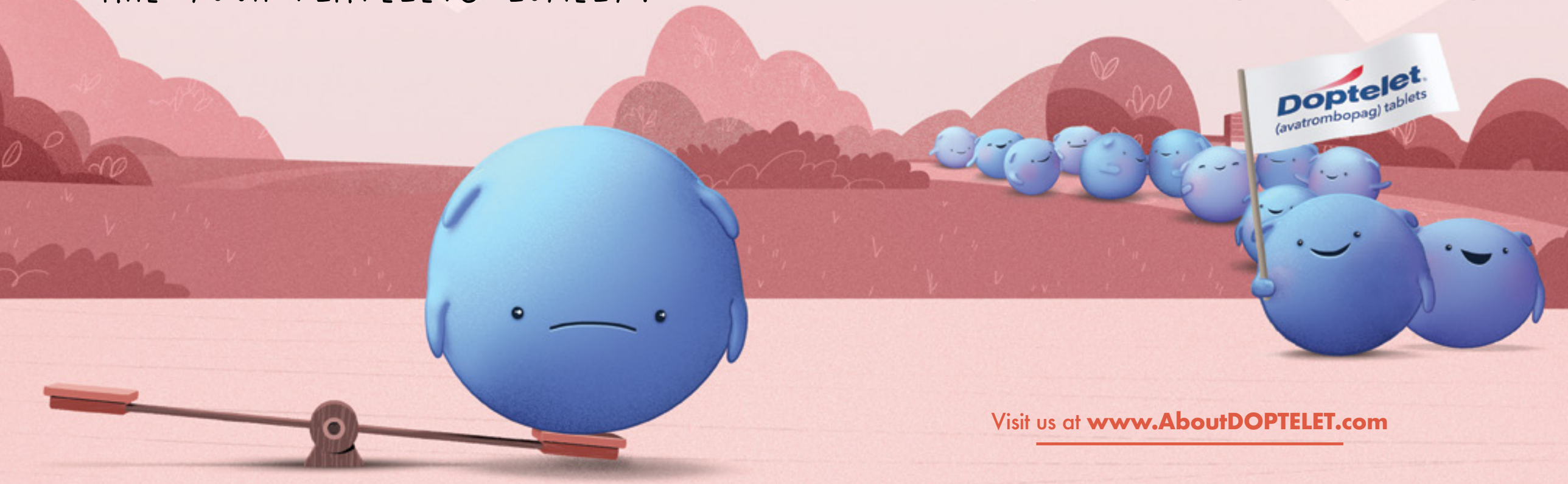
Turn to p. 15 for Barbara's tips.

PHOTOS BY TOLGA KAVUT

For adult patients with chronic immune thrombocytopenia (ITP) when other treatments have not worked well enough

ARE YOUR PLATELETS LONELY?

Boost and maintain platelet counts with DOPTELET, a convenient tablet taken with any food, any time of day*



Visit us at **www.AboutDOPTELET.com**

*When you start DOPTELET, your doctor will check your platelet counts every week. Based on the results of these tests, your doctor may make adjustments to your dose until you reach a stable platelet count of 50,000 platelets per microliter or more. Then your doctor will check your platelet counts every month.

What is DOPTELET® (avatrombopag)?

DOPTELET is a prescription medicine used to treat low blood platelet counts in adults with chronic immune thrombocytopenia (ITP) when other treatments have not worked well enough.

DOPTELET is not used to make platelet counts normal in adults with chronic immune thrombocytopenia. It is not known if DOPTELET is safe and effective in children.

IMPORTANT SAFETY INFORMATION FOR DOPTELET

What are the possible side effects of DOPTELET?

- DOPTELET may cause serious side effects, including blood clots. People with chronic immune thrombocytopenia and people with certain blood clotting conditions may have an increased risk of developing blood clots. Tell your healthcare provider right away if you have signs and symptoms of a blood clot, including swelling; pain or tenderness in your leg; shortness of breath; chest pain; fast heartbeat; or stomach (abdominal) pain or tenderness.
- The most common side effects of DOPTELET when used to treat low blood platelet counts in adults with ITP are headache, tiredness, bruising, nosebleeds, upper-respiratory tract infection, joint pain, gum bleeding, purple or red spots on your skin, and a runny nose. These are not all the possible side effects of DOPTELET.

Before you take DOPTELET, tell your healthcare provider about all of your medical conditions, including if you:

- have ever had a blood clot.
- are pregnant or plan to become pregnant. DOPTELET may harm your unborn baby. Tell your healthcare provider if you become pregnant or think you may be pregnant during treatment with DOPTELET.
- are breastfeeding or plan to breastfeed. It is not known if DOPTELET passes into your breast milk. Do not breastfeed during your treatment with DOPTELET and for at least 2 weeks after the last dose. Talk to your healthcare provider about the best way to feed your baby during this time.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. DOPTELET may affect the way other medicines work, and other medicines may affect the way DOPTELET works.

For more Important Safety Information, please see Summary of Information on the following page.

Call your doctor for medical advice about side effects. You are encouraged to report side effects to FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Feeling healthy—and positive—despite ITP

Diagnosed with ITP at age four, Barbara Pruitt has hardly known life without the condition. Yet, thriving comes naturally!

Choose "cheerful." Nearly six decades of having ITP has led Barbara to live by this philosophy: "You have the option to be cheerful or miserable—why would you choose miserable? Why would anybody choose that? I haven't lived my life feeling like a victim [because of ITP]—and I think it's a shame when people do. It prevents them from enjoying a lot of the wonderful things in life."

Adapt fun and fulfilling activities. "Educate yourself about ITP so you understand your limitations, but don't dwell on them. Find other things that are fulfilling for you," Barbara suggests. She recalls the time her husband and children were planning to go scuba diving. She discussed the outing with her hematologist, who advised her that the atmospheric pressure increased the deeper you go, making it unsafe for her. "So, I skin dive, which is essentially snorkeling, and stay near the surface of the water," she says. "I didn't *need* to go deep—I could see the reefs from where I was!"

Find the right care for you. Over the years, Barbara, a retired nurse, has worked with a number of specialists. "I feel like I've been fortunate—I've had very good hematologists." She urges people newly diagnosed with ITP: "Shop around for a hematologist. Consider this a long-term relationship. If you can't communicate well with your doctor—if he or she isn't listening to you—you need to find someone who will."

Don't scare yourself. "I realize when I'm driving, I can't afford to get into an accident. I can't afford to trip and fall," Barbara admits. "I could scare myself every day, but I don't. I'm here and I have a choice about how I live my life." As she tells others with ITP: "You will be okay!"

Accept your normal. "I was explaining to someone all the things I do without thinking about it before coming down for breakfast each day: I check my pillows for signs of blood. In the bathroom mirror, I check my mouth to see if there's blood. I brush my teeth, I spit into the sink—*are my gums bleeding? Is there blood in my urine or in a bowel movement?* I get in the shower—*how many bruises do I have today? Oh, that one's getting better.* Looking at my legs, *how bad are the petechiae—are they up to my knees or have they gone higher?"* It's a once-daily check for red flags, she says. "They tell me when I've overdone it—that my body is fatigued and I need to take it easy that day, lie down in bed and read or watch old movies." They remind her, she says, "I can't overdo!"


"I could scare myself every day, but I don't," says Barbara, with grandsons Jack (in her arms) and William. "I have a choice about how I live my life."

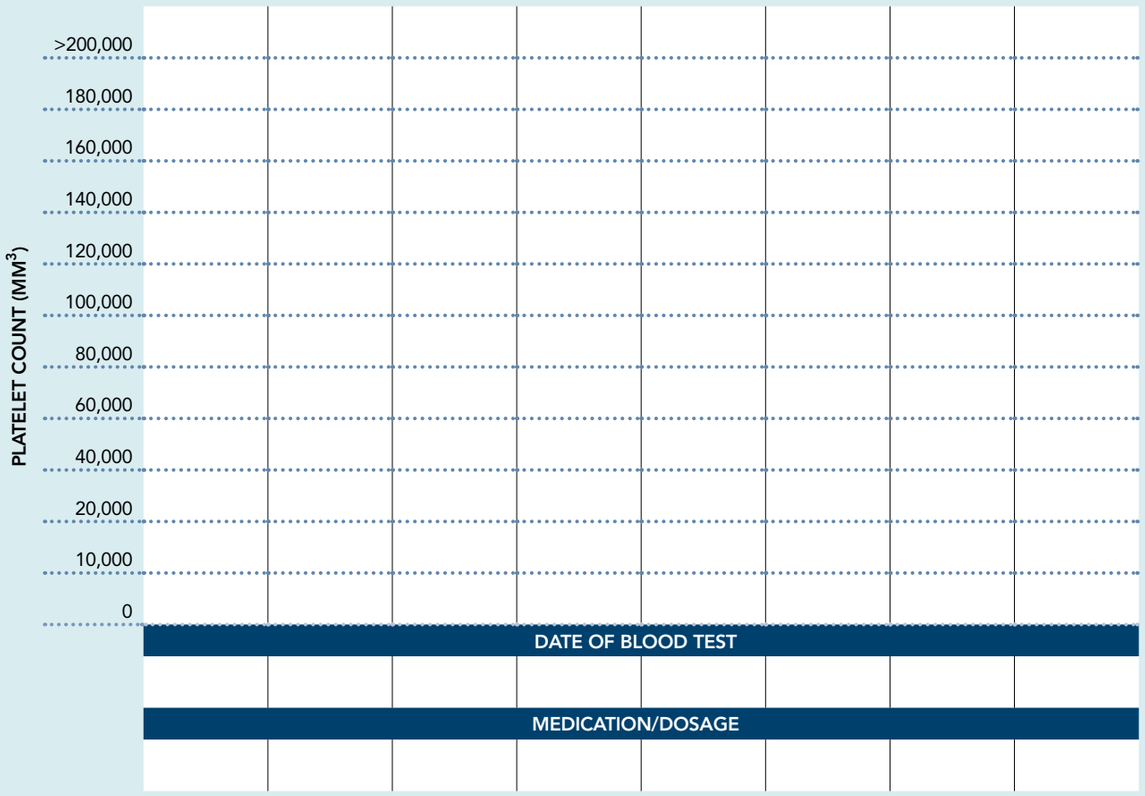
Get your sleep. When she had children at home, Barbara often managed her days slightly sleep-deprived. "For many years, your life is running you and you're not running your life," she laughs. "Now, I can sleep in in the morning. It's liberating! With an autoimmune illness, rest is very important. I'm more careful about my bedtime. I consider sleep as a present to myself and try to get at least eight hours a night."

My ITP trackers

Help your healthcare provider get a better idea of your ITP symptoms and how well your current treatment (if any) may be working. Fill out these worksheets and take them to your next appointment.

Plot your platelet count

After each blood test, mark your results.



How are you feeling?

Help your care team understand how ITP affects you.
Fill out the worksheet below and take it to your next appointment.

1. In the past month, I've felt:

Symptom	Doesn't affect me	Rarely	A few times per week	Daily	Multiple times per day
Purple bruises on the skin (purpura)					
Tiny red or purple dots on the skin (petechiae)					
Blood-filled blisters inside the mouth (wet purpura)					
Bleeding from the gums (e.g., while brushing teeth or during dental work)					
Blood in urine or stool					
Heavy menstrual bleeding					
Excessive bleeding from wounds or cuts					
Lumps of clotted blood under the skin (hematoma)					
Fatigue					

2. I am satisfied with my:

	Yes	No	Somewhat
Energy levels			
Stress levels			
Sleep			
Physical appearance			
Activity level			
Family life			
Social life			
Work life			
Overall quality of life			

3. These tend to trigger my ITP symptoms:

	Yes	No
Stress		
Illness		
Allergies		
Other (list)		

Make extra copies of these worksheets

4. I have also been diagnosed with (Indicate any other conditions or diseases you may have):

_____

"ITP keep us down? *No way!*"

Trish, Marci and Bob have rallied after their run-ins with ITP, and today they are thriving. Here, they share the strategies that help them stay strong and feel their best. Ask your healthcare provider if they might work for you, too.

"Pay attention to your symptoms"

Trish Beattie Santaromana
Chicago, IL
Diagnosed with ITP in 2002

Trish never expected to hear she had ITP—especially since she'd never heard of the condition!—when she went to her primary care doctor 18 years ago to investigate red spots (petechiae) on her shoulders and arms. Two hours after arriving home from the doctor's office where she'd had blood drawn, Trish got a call with instructions to head immediately to the hospital to be admitted. "My platelets were at 6K and I was at risk for spontaneous bleeding," she says. "At the time, I didn't know what a platelet was!"

Be your own advocate. "If you don't feel what your doctor wants to do is right for you, question them. At one point my doctor was pushing me to get my spleen removed. I asked, 'Is that going to fix [my ITP]?' She said, 'Well, there's a 60% chance [it will].' " Trish refused the surgery. "You have to be your own advocate." Trish has been willing, however, to try a number of treatments, including a platelet-boosting medication that worked well for her. These days, her platelets are at a healthy range.

Trish, shown here with Felix, tells others with ITP: "Focus on the symptoms, not the numbers."

PHOTO BY CHRIS OCKEN PHOTOGRAPHY

Focus on your symptoms. "If anything strange is going on—for example, if you're having very heavy periods or severe bloody noses—don't ignore it. Look into it," says Trish. "But know there are people walking around with platelets under 10K and they're fine." It took some time before Trish understood that, she acknowledges. "At first, my doctor would send me to the ER when my counts fell below 20K," she says. "I'd feel fine! In time, I just knew to be more careful. It is possible to live with low numbers!"

"Go easy on yourself"

Marci Mayhew
Clare, MI
Diagnosed with ITP in 1983

Marci was five when she was diagnosed with ITP. In the years that followed, she'd ride two miles over a dirt road to visit a friend—no helmet. Since then, she's become more cautious, especially when her platelets are low. Still, she tells parents who have children with ITP, "The more you can let your child [with ITP] live normally, the more resilient they'll be." These days, Marci is a facilitator of a PDSA support group in Clare, MI, and is currently participating in a clinical trial of an ITP therapy. "I don't let ITP hold me back or prevent me from living the life I want to live!"

Keep your sense of humor. "I'm not a 'poor me' type of person, so I try to keep my sense of humor about ITP," says Marci. "Recently, I had my platelets checked and the test revealed 'one large platelet.' I joked about that with my nurse!" Since fatigue is a constant companion, Marci strives to be realistic (and stay mellow) about things like housekeeping. "My house is always a mess, but I can't stress about it," she says. "I've come to terms with the fact that's just the way it's got to be."

Have at least one support person. "My mom is mine," says Marci. "She comes with me to doctor's appointments. She knows how ITP affects me. We travel together and she understands that I have to build 'rest' into our trip." In addition to her mother and support group members, Marci also receives help and encouragement from "regulars" on three Facebook ITP support group pages.

Make things easy on yourself. "My hematologist wrote a standing order for platelet counts, so any time I feel the need to get them checked, I don't have to call the doctor's office—I can just go to the hospital lab and get them done." To check lab results, she simply visits the hospital portal.

"It's okay not to stress about stuff like a messy house!" says Marci, who prioritizes rest when she feels fatigued.

PHOTO BY RYAN WATKINS

"Learn all you can about ITP"

Bob Monigle
Rochester, NY
Diagnosed with ITP in 1999

Oral steroids and IVIG—"the only treatments at the time"—boosted Bob's platelets to a healthy 300-400K range after he was initially diagnosed with ITP 21 years ago. But almost a year later, before a planned family trip to Vail, CO, Bob's platelets crashed again. After a splenectomy, his counts rebounded to normal, but Bob would experience two more platelet crashes—in 2006 and 2018. "I had blood blisters on the insides of my cheeks, nose bleeds and petechiae over my whole body," he says. "It looked like I had a case of the measles—there were red spots everywhere!" The platelet-boosting medication he took following his last crash worked so well he was able to stop the medication altogether. "Since then, my counts have been normal," says Bob, who still gets his platelets checked every three months.

"Know your own limits," says Bob, who enjoys a good game of pool without stress.

PHOTO BY JOHN SCHLIA PHOTOGRAPHY

Get educated. "With the wonders of the internet, it's easy now to educate yourself and be your own health advocate," says Bob, who lacked this resource when he was diagnosed. "Know what ITP treatments are out there," he tells others with ITP. "Make sure you have as much information as possible going into your appointments because you may read about something your doctor isn't aware of."

Listen to your body. "I've learned to adopt a new standard in terms of my energy levels," says Bob. "You tell your body, *Okay, I'm not going to overdo.* I used to be the one going out in the yard cleaning up. Now I call my boys over on the weekend and have them help me. I know my limits."

Get support. "With my last ITP flare [in 2018], I said, *Now, it's time for me to take more action.* So I became a facilitator for a local PDSA ITP support group," says Bob. "ITP is a rare condition, and it's important to find others with whom you can share information and commiserate, and a place where you can get information on treatments. One of the men in my support group didn't develop ITP until he was in his 60s! And some people have to adjust to a 'new normal' of having platelet counts below 50K on a daily basis. That's where a support group can help!"

Make sure your doctors are in sync. After his 2018 platelet crash, Bob was hospitalized and treated by hematologists who didn't know his treatment history—specifically, that a certain medication combo had already been shown to be ineffective in him. "I insisted they talk to my regular hematologist-oncologist who works in the hospital's cancer center!"

Reap the *mind and body* benefits of meditation

Changing jobs. Buying a new house. Going through a breakup. Stressful situations trigger the release of cortisol, a hormone that raises levels of inflammation. And according to the Platelet Disorder Support Association, research suggests that physical or psychological stress, and the resulting oxidative stress in the body, may also trigger episodes of ITP and worsen fatigue. To take the edge off, try this simple meditation, which promotes peaceful balance by keeping your mind attuned to the present.

Find a quiet place to sit and close your eyes, then…

- **Tune into your current state.**
  Become aware of your surroundings and notice thoughts as they come up. Acknowledge feelings, then let them pass.
- **Focus on your breath.**
  For 60 seconds, notice the pattern of your breathing from your lungs to your stomach.
- **Concentrate on your whole body.**
  Expand your awareness into what you're feeling physically.
- **Expand into your environment.**
  Notice what's in your immediate surroundings, such as sounds. Be present in the moment.

Once done, open your eyes slowly and try to bring that mindfulness with you for the rest of the day.

These resources can help!

If you're confused about ITP or wish you knew someone who gets what you're feeling, take heart: Knowledge, support and comfort are readily available—and just a click away. Check out our partners below, along with other great resources.

OUR PARTNER:
The Platelet Disorder Support Association
is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research, support and communication. Our organization is devoted to offering the most timely, accurate and comprehensive information for medical professionals and patients with ITP and other platelet disorders.
www.pdsa.org

Platelet Disorder Support Association
Empowering ITP Patients

- **Immunoglobulin Nursing Society**
  ig-ns.org
- **The Daisy Foundation**
  daisyfoundation.org
- **Infusion Nurses Society**
  ins1.org
- **National Organization for Rare Disorders**
  rarediseases.org

Questions to ask today

When you have ITP, getting the best possible care means talking openly to your doctor about it. Get the conversation started with these questions:

1. Could my symptoms mean I have ITP? If so, could it be chronic ITP? How do you know?_____

2. What kind of testing do I need? How often will I need it?_____

3. What is a safe platelet level for me?_____

4. At what platelet level will I need treatment?_____

5. What treatment do you recommend, and why?_____

6. If that treatment doesn't work, are there any other therapies that you'd recommend?_____

7. Are there activities or medications that I should avoid?_____

8. Are there lifestyle strategies that can help keep my symptoms at bay?_____

9. What symptoms should I report to you and when?_____

10. What symptoms should make me seek emergency care?_____