

BEAT FATIGUE TO MAKE EVERY DAY BETTER!

PATIENT GUIDE TO

ITP

A low blood platelet disorder

Health**monitor**®

VOL.2, NO.1

16 ways to
have a
**FUN, SAFE
SUMMER!**

**KNOW
YOUR
TREATMENT
OPTIONS**

Guide2ITP.com

COMPLIMENTS OF:

**“Look
at me!”**

In remission for
nine years,
Caroline Kruse is
proof you can
have a happy,
active life
with ITP

 **PDSA**
PLATELET DISORDER
SUPPORT ASSOCIATION
for People with ITP

ITP

A low blood platelet disorder



You can thrive with ITP! Effective treatments are making it more possible than ever.

Cover photograph by Cheryl Debono.

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For more info to thrive with ITP, go to Guide2ITP.com. Here you'll find our exclusive platelet tracker, nutrition-boosting recipes and an active life guide to help you make the most of every day!

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LIVING WELL—AND LOVING LIFE

with ITP!

Caroline Kruse will never forget the 2 a.m. phone call that changed her life: “It was the doctor on call. I’d had my blood tested earlier in the day, and it showed that my platelets were 2,000. He said I must immediately go to the emergency room—do not take a shower, do not shave my legs, do not brush my teeth,” she recalls.

Fast forward 12 years to today, and Caroline is the very picture of energy. In remission from immune thrombocytopenia (ITP), she spends long days balancing family—she has one child in high school and one in college—with her career as executive director of the Platelet Disorder Support Association (PDSA).

“I work long hours and sometimes it is a seven-day-a-week job, but I love what I do and am very passionate about helping

other patients and families struggling with ITP.”

Finding the treatment that works for her has made it possible for Caroline to keep up with her hectic schedule. Once a month, she travels from her Cleveland home to PDSA’s Washington, DC, offices, and throughout the year she attends medical meetings all over the globe.

It’s an amazing turnaround from those days when she struggled with the bruises, rashes and energy drain that put her life on hold. “I had chronic ITP for three years with extreme fatigue,” she says.

Today, Caroline wants others with ITP to know they don’t have to suffer needlessly. “New treatments are available,” she says. “I tell people, ‘Look at me. I’ve been in remission for nine years. There is always hope.’”



“New treatments are available. If something isn’t working, there might be something else out there for you.”

—Caroline Kruse,
living with ITP since 2000.

What is ITP? ITP, or immune thrombocytopenia, is an autoimmune disease in which the body attacks and destroys platelets, cells that play a role in blood clotting. As a result, platelet counts can plummet, putting you

at risk for spontaneous bleeding and bruising.

What happens in ITP? Normally, special cells in the bone marrow produce platelets, which circulate in your bloodstream for

● ITP basics

about 10 days before being removed from the body. But in a person with ITP, platelets are removed more quickly than normal, causing platelet counts to drop to levels as low as 10,000/microliter of blood or less. (See “Understanding your platelet count,” opposite.) Research also reveals that many people with ITP also have trouble producing enough platelets.

As a result, your blood has trouble forming clots, leading to bleeding symptoms and bruises. In general, the lower your platelet count, the more bleeding symptoms you’ll have. You may notice purpura (bleeding under the skin), which includes bruises or tiny reddish-purple


spots (called petechiae). Nosebleeds, bleeding gums and heavy menstrual bleeding can also be a problem. (See “Handle bleeding episodes with confidence” on page 22.) And the disease can take an emotional toll: When your platelet count fluctuates, you may feel anxious, depressed or fatigued.

Who gets ITP? ITP affects women more than men, and may strike at any age.

How is ITP diagnosed?

To diagnose ITP, your healthcare provider must rule out other causes of a low platelet count, such as infections or bone marrow diseases, so he will review your medical history, conduct a physical exam and order blood tests. No specific test can prove that you have ITP, but the diagnosis can be confirmed by observing how you respond to ITP treatments.

How long does ITP last?

It depends on the type of ITP you have. Acute ITP usually lasts fewer than four months and is more common in children. When present for more than 12 months, it is referred to as chronic ITP and may last for years. Fortunately, treatments are available for almost all patients that can boost your platelet count and restore your health. But it can take time to find the best treatment, so it’s important to partner closely with your healthcare team and to be patient. 

Understanding your PLATELET COUNT

When you have ITP, you will become familiar with a blood test called a platelet count, which measures the number of platelets in your blood and their ability to function. What’s considered a “safe” platelet count can vary. Ask your doctor about the healthiest count for you.

Platelet count and what it means

140,000 to 400,000

Normal

100,000-139,000

Fewer than normal, but rarely a risk for bleeding or need for monitoring by your doctor. Not considered low enough to be “ITP.”

30,000 to 99,000

Fewer than normal, but rarely a risk for bleeding. May need to be monitored by your doctor but rarely requires chronic treatment.

10,000 to 29,000

You have an increased risk of minor/moderate bleeding and require close monitoring. You will also likely require treatment.

Fewer than 10,000

Your ITP is severe, and you’re at high risk for spontaneous bleeding. Treatment and possibly even hospitalization may be necessary.

KNOW YOUR SYMPTOMS

Check any of the items that apply to you and review the answers with your doctor at your next visit.

I’ve noticed the following marks on my skin:

- Pinpoint-sized reddish-purplish spots (called petechiae)
- Large bruises (called ecchymosis), especially on my arms and legs, from minor bumps
- Bruising or blood-red spots in my mouth
- A lump of clotted—or partially clotted—blood under my skin (called a hematoma)

I’ve also been having these symptoms:

- Nosebleeds
- Bleeding gums
- Blood in my urine or stool
- Heavy menstrual bleeding
- Prolonged bleeding from cuts
- Coughing up blood clots





Know your TREATMENT OPTIONS


However, if you need treatment, his top priority will be to raise your platelet counts. To do that, he may prescribe a steroid medication—usually prednisone—to suppress your immune system. He may also recommend treatment with a blood product, such as IVIg or anti-D immunoglobulin, which raise platelet levels for a short period.

If your initial treatment fails, your doctor may recommend one of the following:

- **Anti-CD20 monoclonal antibodies.** These work by disabling and changing specific immune system cells.
- **Splenectomy.** If you have chronic ITP, your hematologist may recommend that you have your spleen removed. Without your spleen, your platelet levels are likely to rise. (Surgery results in higher platelet counts about 66% of the time.) However, splenectomy is a serious procedure and may work best in those under 40.
- **Platelet growth factors.** This class of medicine works in a different way: Instead of lowering

the number of platelets destroyed, it boosts platelet production.

○ **Chemotherapy.** While this treatment is best known for treating cancer, its ability to suppress the immune system can sometimes benefit people with ITP.

Keep in mind that every patient is different—how well you respond to treatment depends on many factors, such as your age, platelet count and bleeding history. It's also common to try more than one. Work with your hematologist to find the treatment that works for you. 

MEDICATION BREAKTHROUGH!

The latest drugs increase platelet production

Until recently, treatment has focused on slowing platelet destruction. Now a new class of drugs, called platelet growth factors or TPO receptor agonists, actually stimulate your body's production of new platelets. This treatment may help keep your counts at normal or near-normal levels.

Remember!
You are the most important part of your treatment team. Take an active role in managing your care.

Recent advances

make it easier to conquer the challenge of having ITP.

Once you have been diagnosed with ITP, your hematologist (a doctor who specializes in blood disorders) will consider your symptoms. If you are experiencing only mild bruising and petechiae, he may want to simply observe you for the time being.

Your ITP healthcare team

These professionals can help you cope with the physical and emotional effects of ITP:

- **Primary care physician:** prescribes medication and can refer you to a specialist when necessary.
- **Hematologist:** diagnoses and treats ITP, as well as other blood diseases and disorders.
- **Psychologist:** helps you cope with the emotional challenges of living with ITP.
- **Nurse/nurse practitioner (NP)/physician assistant (PA):** works with your doctor to offer routine medical care; serves as your advocate and educator.



● you and your healthcare team

How MEDICATION can help

	Medication	How it's administered	How it works
FIRST-LINE	Corticosteroid	IV infusion, pill, injection	Raises platelet count by suppressing the immune system.
	Intravenous immunoglobulin-IVIg (a blood product)	IV infusion	Increases platelet count for up to a few weeks.
	Anti-D immunoglobulin (a blood product)	IV infusion	Binds to red blood cells, temporarily boosting platelet count.
SECOND-LINE	Platelet growth factor	Injection, pill	Stimulates bone marrow to produce more platelets.
	Anti-CD20 monoclonal antibody	IV infusion	Disables and changes specific immune system cells, reducing antibody production and boosting the platelet count.
	Immunosuppressant medication	IV infusion, pill, injection	Disables parts of the immune system and raises platelet count.
	Chemotherapy	IV infusion, pill, injection	Slows cell growth and suppresses the immune system.



QUESTIONS for your healthcare team

Ask these important questions at your next appointment:

1. What are the results of my blood tests?

2. What's my platelet count?

3. What are my treatment options?

4. What effect will different therapies have on my platelet count?

5. Which treatment do you recommend?

6. When will I know if my treatment is working?

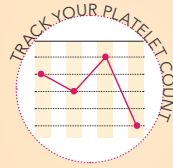
7. How often should I get my platelet count checked?

8. Are there any side effects I should tell you about immediately?

9. Are there any lifestyle changes I should make?

10. When should I come back for a checkup?

- you and your healthcare team



How well is your

TREATMENT working?

Use this worksheet to track your platelet counts.

Date my treatment began: _____

Starting platelet count: _____

Date of blood test >>

100,000+ per microliter of blood				
90,000				
80,000				
70,000				
60,000				
50,000				
40,000				
30,000				
20,000				
10,000				
0				

ITP Help on the Go

Download our free iPhone app to record your info wherever you are. Track your platelet counts, chart your progress, schedule events, share info with your doctor and more.



To download our app and get more useful tools and info visit **Guide2ITP.com**. A sampling of what you'll find:

- ▶ **Downloadable platelet tracker**
A printable worksheet to plot the results of your blood tests and monitor your progress
- ▶ **Treatment essentials**
The info you need about treatment options and strategies to control your ITP
- ▶ **Nutrition boosters**
Delicious recipes and tips to get critical nutrients for strengthening your immune system
- ▶ **Active life guide**
Info to live safely, whether it's managing everyday tasks, enjoying exercise or traveling

- get inspired

ITP CAN'T BRING ME DOWN!

Marjorie Ligelis, 63, of Bowie, MD, has struggled with fluctuating platelet counts for 14 years. A year ago, her platelets had plunged to 4,000—the lowest they've ever been. Yet she always bounces back because “being happy is first and foremost,” says Marjorie. Here, she shares her strategies for living life to the fullest with ITP:

1 Call on your inner optimist. “What has helped me most in dealing with ITP is seeing the glass as half full. I know there are a lot more treatment options now than when I was first diagnosed in 1998.”

It works! Optimistic women live longer than pessimistic women, concluded University of Pittsburgh researchers after reviewing eight years of data from the Women's Health Initiative, a government study of more than 100,000 women over age 50 that began in 1994. In separate studies, researchers linked optimism with healthier lifestyle behaviors, such as not smoking and being physically active.

2 Don't dwell on your disease. “Other than getting my platelets checked once a month, I try not to think about my ITP. I go on with my life just like everyone else.”

Can't stop thinking about ITP? Take a 10-minute timeout. Look up some friends on Facebook... make a list...remember the last five places you visited. Focusing on something else for a few minutes can break your thinking pattern.

3 Find joy. “It's important to find something that makes you happy so you can deal with the ups and downs of ITP.” For Marjorie, that means spending most weekends with her husband in Ocean City, MD, where she reads, relaxes and catches sea spray. “I lie in bed and watch the sun rise over the ocean. I am very grateful that I'm able to regroup and clear my mind for the start of another week.”

4 Do what you love. “It's important to enjoy what you do. I love my work.”

Job-hunting? Consider a position that involves helping people.



One of Marjorie's well-being secrets? Her pets!

“My six Yorkshire Terriers relax me because they give me unconditional love.

When I have a bad day, it feels good to come home to them.”



7 Keep testing new treatments.

“You have to take an active role in getting the best medical care you can,” says Marjorie, who, along with trying several treatments, has participated in clinical trials.

8 Befriend your doctor.

Having an ongoing dialogue with a doctor you feel comfortable with is important, says Marjorie. “I have been with my doctor for 12 years, and she always responds to me when I need her.” 🐾

Research shows those who serve others, like Marjorie, are happiest with their jobs.

5 Stay connected. Talking to other ITP patients “helps confirm that you're not the only one going through this,” says Marjorie.

6 Remember it's all relative. “I've gotten through a lot of low counts by realizing that other people don't die when their platelets are at an alarmingly low level. A lot of people freak out when their platelets are at 30,000, but I've been happy at that count.”

Thrive!

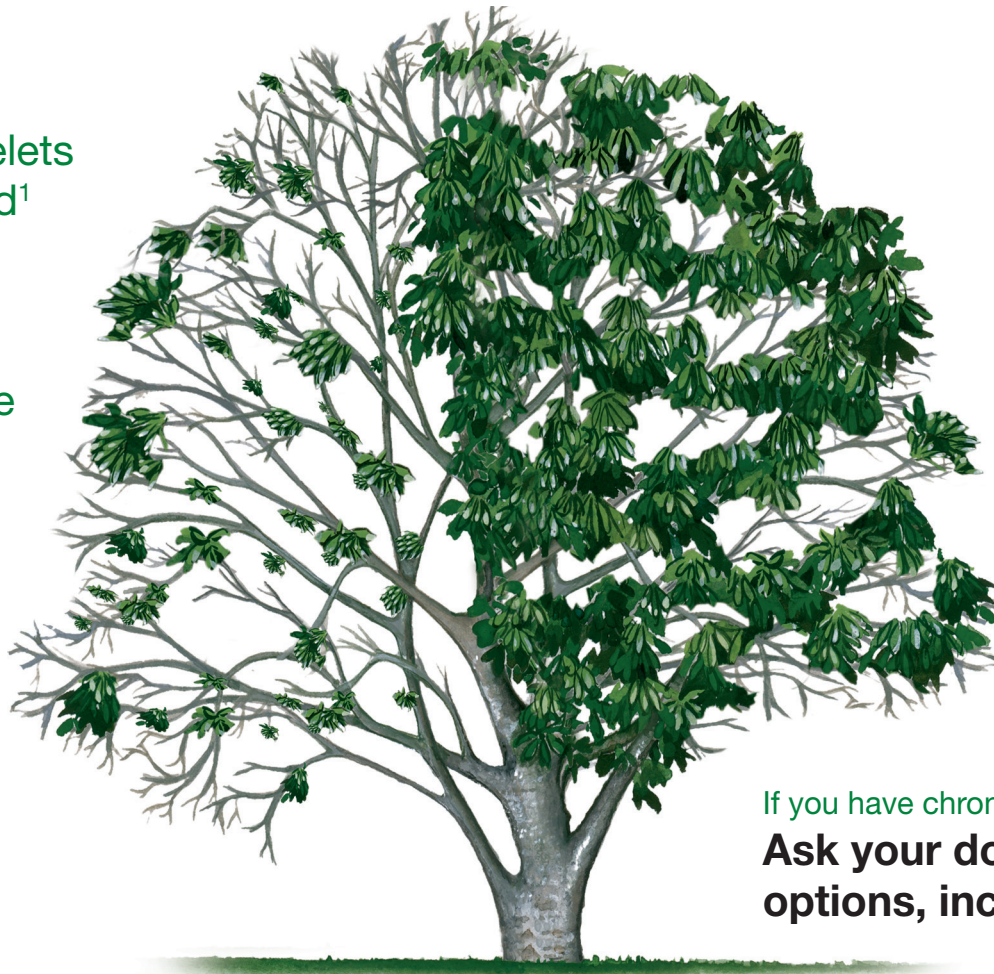
For treatment information and to learn how others are living a full life with ITP, go to Guide2ITP.com.

In chronic ITP,

Knowledge can help grow your platelet counts

In ITP:

- ▼ Healthy platelets are destroyed¹
- and*
- ▼ The body doesn't make enough new platelets¹



For ITP,

Treatments raise platelet counts by *either*¹:

- ▲ Affecting the immune system to reduce platelet destruction
- or*
- ▲ Activating a process to boost platelet production

If you have chronic ITP,

Ask your doctor about ITP treatment options, including platelet boosters.

To find out more, please visit: www.ITPanswers.com

BEAT FATIGUE

with words of wisdom from the ITP experts

Wouldn't it be great if somebody showed you how to do everything from keep your energy up to get your family to pitch in? Sure, you can get that kind of help from your healthcare team, but don't overlook a special resource: an ITP support group. Group leaders, or facilitators, also have ITP, so you'll get a dose of real-world experience and empathy from members and leaders alike!



Linda Guy-McGuirl,
Basking Ridge, NJ, group facilitator
Living with ITP since 1985

Best tips

Train your family. With ITP, one day you feel fine, and the next day you can feel exhausted. Getting family to pitch in can be a great help. Ask them to do specific tasks (unload the dishwasher, fold the laundry, etc.), so you can take the time you need to reenergize.

Get your treatments on time. My platelets are very low—between 2,000 and 5,000—and my fatigue is very prominent. So it's important for me to stay on schedule with my therapy. It's also critical to work with your doctor and to talk about your fatigue and any other symptoms you have in case your therapy needs to be adjusted. You really have to take charge of your healthcare and make sure you get the treatment you need.

“To have a rare illness and be able to learn about it is so valuable. Meeting with others makes you feel like you can live with this disease.”

Georgia Valvano,

Succasunna, NJ, group member
Living with ITP since 2001

Best tips

Rest when you need to rest. I work full-time and tend to push myself. But Linda has let me know it's okay to rest when you need to rest. And my husband, who comes to meetings with me and knows about the fatigue that comes with ITP, will tell me to go lie down.

Keep a standing order for blood work at the lab.

If my legs get achy or I start bruising, I know it's time to get my counts done. Because I have a standing order for blood work at the lab, I can go first thing in the morning, the technicians know what I need, and I'm in and out in five minutes. They fax my results to the doctor the next day and my doctor's office calls me. It makes things easier—I don't have to take off work and go to the doctor first. 📞



“I'm still active, and I do what I can do. If my energy levels are low, I just improvise!”

Eating for energy!

Nutrition plays a role in keeping you vibrant and on-the-go. Visit Guide2ITP.com for delicious energy-boosting recipes.

“I DO WHAT I LOVE— with peace of mind!”

Beth Siegelbaum’s mountain bike really got a beating last summer. With husband, Ed Holowinko, in tow, she pedaled for six days on Prince Edward Island’s Confederation Trail, a packed-dirt path that winds alongside rivers and through wetlands and hardwood groves. Together, the couple

“I don’t feel bad anymore. I just roll with the punches and do what I have to do.”

racked up 200 miles, and Beth’s only concern was keeping her tires pumped up. Vacations weren’t always so anxiety-free for the Norwalk, CT, couple. A few years back, Beth would take off with her family only to find she needed to have her blood checked—and receive an infusion for her ITP—right in the middle of her vacation! “I got to see the insides of hospitals in Sedona, AZ, Gunnison, CO, and Savannah, GA,” she quips. But staying abreast of new ITP therapies and working with a doctor who welcomes her input have helped the avid cyclist

find a medication that works for her. Now, Beth books her vacations without fear.

A wedding—and a wake-up call! Diagnosed with ITP in the early ’90s, Beth, a retired computer programmer turned X-ray technologist, was at first only mildly bothered by her low platelet count, which for years ranged between 70,000 and 90,000. “It was not alarming,” she says. “I got lax about it because I was stable—and I’d actually forget to get my blood checked.”

But after getting her blood tested for a marriage license in May 2000, Beth was ordered to hightail it to a hematologist: Her platelets were down to 22,000. “Since that time, my platelets never came up again by themselves. Without treatment, they stay around 3,000.”

A new path to tranquility When Beth learned of a new therapy at an ITP conference, she asked her doctor about it and



Feeling sluggish?
Just start moving, Beth says. “You’ll usually find the energy to continue.”

they agreed to give it a try. The goal of the therapy is to boost her platelet count to 50,000. Her legs, Beth adds, are her “petechiaeometer”—when petechiae there are dense, she knows her counts are low and she needs to see her doctor.

Now, Beth gets an injection every Thursday morning and visits her doctor monthly for a checkup and blood test. “It’s a lot more convenient than what I was doing before,” she says. And mid-vacation infusions are a thing of the past.

Living a normal life “Sometimes, I wonder if I’m in denial, but, with this medication, I don’t feel bad anymore. I just roll with the punches,” Beth remarks. That includes taking 20-mile rides every weekend with Ed on their low-to-the-ground recumbent trikes, which always get a lot of attention on the trails!

“That would be my advice to people with ITP,” Beth adds. “Live your life as normally as you can. Be educated about your condition and do what you have to do, but don’t let it run your life.”

- every day with ITP

Handle bleeding episodes WITH CONFIDENCE

It usually takes some sort of mishap—a scratch or a bump—to cause bleeding, but when you have ITP you can bleed for no reason at all, especially from the nose and mouth. Luckily, we’ve gathered the info that shows you how to take charge.

Note: Let your doctor know about any bleeding episode—it may be a sign your platelet count is low. She may adjust your therapy or prescribe meds to stop the bleeding.

Nosebleed

Head it off: Keep nasal passages supple—use a humidifier year-round to keep moisture in the air. At bedtime, smear a thin layer of water-based lubricant or antibiotic ointment inside nostrils; use a saline nasal spray or nose drops two or three times a day



to keep nasal passages moist. Avoid blowing your nose too hard and try an over-the-counter nasal decongestant spray containing oxymetazoline—it helps constrict blood vessels to prevent bleeding.

- **MAKE IT STOP:**
 1. Sit upright and lean forward slightly to prevent blood from streaming down your throat.
 2. Pinch your nostrils shut for 10 minutes to help stop the blood flow.
 3. When you release your nose, keep your head elevated over the level of your heart—don’t bend over or lie back.
 4. If bleeding continues, pinch your nose again and repeat the steps.

Call your doctor if: Bleeding persists for 20 minutes.

Call 911 if: Your nosebleed has been triggered by a head injury.




Bleeding from the mouth

Head it off. Keep your teeth and gums healthy by brushing twice a day with a soft toothbrush. Brush gently and don’t skimp on the toothpaste. To remove plaque and food debris between teeth, use interdental brushes—they’re softer and won’t cut into your gums the way floss can.

Tip: Opt for thinner “picks,” found at grocery and drugstores; they’re easier to insert between teeth.

- **MAKE IT STOP:**
 1. Bite down on a cool, damp tea bag or use your fingers to press a gauze pad soaked in ice water onto bleeding gums.
 2. Hold this position for several minutes.
 3. When your bleeding has stopped, take in food and beverages that are room temperature or cooler. Avoid hot drinks and food, which can trigger bleeding to start again.

Call your doctor if: Bleeding doesn’t stop or you develop swelling of the tongue, neck or throat.

Call 911 if: You have difficulty breathing or swallowing. 

Remember!

Tell your dentist that you have a bleeding disorder so he can treat you safely and appropriately.

For brain bleeds, get immediate medical care!

Call 911 if you experience a head injury or if you notice any of these symptoms:

- a headache that won’t go away
- dizziness
- vomiting
- unusual sleepiness
- confusion
- slurred speech
- eyes not moving together
- weakness on one side of the body
- stiff neck or back
- seizures
- you can’t see or hear

WEB EXTRA!

Are you a woman with ITP? Learn more about heavy menstrual bleeding, also called menorrhagia, at Guide2ITP.com/basics

ENJOY YOURSELF THIS SUMMER!

Make your days under the sun safe and fun with these tips



◦ **Going on a hike?**

Wear long pants and long sleeves.

This will help shield you from itch-causing poison oak and poison ivy and prevent cuts and scratches caused by twigs, shrubs and rocks.

Don't be a trailblazer! Stick to well-cleared paths. Not only will that keep you from brushing up against itch-causing plants, but you'll also be able to spot and steer clear of any obstacles that could cause you to trip.

Keep the bugs away. Use insect repellent to keep your skin safe from nasty bites. If you head to wooded areas often, consider investing in clothing that contains a special "insect shield" right in the fabric. It's found in sporting goods stores.

◦ **Going on vacation?**

Plan ahead. When New Jersey resident Georgia Valvano plans a trip far from home, she gets a blood test to check her platelets in time to get platelet-boosting therapy if she needs it.

Make a kit.

Include the following:

- 1 A medical ID card that says you have ITP and lists emergency contacts
- 2 Compression bandages and other products that can help stop a bleed
- 3 Saline nasal gel to soothe the nose after a nosebleed
- 4 All your medications in their original containers

Know where the nearest hospital is.

Make sure your destination is not too far from medical care in case of an emergency.

Don't skip the sunscreen!

Exposure to UV rays may trigger petechiae in people with ITP, so you have extra reason to guard against the sun. Apply a broad-spectrum, water-resistant sunscreen with an SPF of at least 30 about a half hour before you go outside. Reapply as needed.



◦ **Taking a dip?**

Slip on swim shoes. They'll protect you against sharp rocks and hidden pointy objects in the surf or sand. And at the pool, they can help you dodge pavement toe-stubs.

Look for a lifeguard. Make it a rule not to swim at any unguarded location. ▶

● every day with ITP

Give coral reefs a wide berth. If you're snorkeling, don't swim too close to the coral. You'll dodge slow-healing cuts and scrapes that can cause a skin infection in addition to bleeding.

○ **Flying somewhere?**

Bring a small washcloth. Tuck between the metal seatbelt buckle and your body to reduce bruising during bumpy landings and takeoffs. Check your

luggage instead of trying to haul it into the overhead bin, and avoid aisle seats, where you're more likely to get bumped by fellow passengers, luggage and carts.

Invest in this must-wear accessory—medical alert jewelry!

It informs medical personnel that you have a bleeding disorder—so they can attend to you properly. 📌

Keep summer carefree for your child with ITP

If your little one is...

...bound for camp

Lighten the backpack! Since straps can dig into shoulders and leave bruises, lighten the load to 10% or even less of your child's bodyweight—so, not more than an 8-pound pack for an 80-pound child. Pick one with wide, padded shoulder straps and a padded back, advises the American Academy of Orthopaedic Surgeons (AAOS). Another idea—try a backpack on wheels.

...playing summer sports

Know how safe it is! High-contact sports—like football and boxing—are poor choices for kids with ITP. But what about tennis? Or softball? Ask your child's doctor about activities that are safe for him and any protective gear he should use.

...bored and it's raining out!

Have him find a friend! Kids can join the PDSA Facebook page, follow it on Twitter or connect with other teens with ITP through the online discussion group for teens at pdsa.org.

Get peace of mind
Inform camp counselors, coaches and anyone else tending to your child about his ITP.



BRUISE-PROOF your home

The problem:

Clutter, clutter everywhere!

The fix: Do a “search and destroy” on home hazards. Eliminate stacks of magazines and books (recycle, or leave your magazines in a gym, laundromat or company cafeteria). Put toys in a toy box. Secure electrical cords. Store paraphernalia like scrapbooking items and dumbbells in an out-of-the-way place. (*Hint:* There's a better place for that exercise bike!)

The problem:

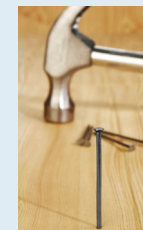
Furniture with sharp edges

The fix: No need to toss Aunt Emma's armoire or the console you lovingly restored! Simply thin out a furniture-heavy room by discarding worn or useless pieces and moving the “bump magnets” you absolutely love out of high-traffic areas. You'll likely find that you love your new room more than before!

The problem:

Slippery floors

The fix: Toss area rugs or secure them with double-face tape or antislip rug mats. Repair loose floorboards and carpeting.



Wipe up spills promptly and use nonskid floor wax.

The problem:

Tippable TVs and furniture

The fix: Check hardware stores and online sources for straps, latches and fixtures designed to secure heavy items like bookshelves and dressers to walls. Anchor TVs and other electronic equipment with safety straps. Set heavy items on sturdy furniture or in cabinets specially made to hold them. 📌



Ask for help!

Need to carry something large, like a package, box or even the laundry basket? Ask for help instead of doing it yourself to avoid tripping or causing a bleed.

- every day with ITP

Insider secrets to a **LONG & HEALTHY LIFE**

Picture your dream retirement—is it on a beach? The mountains? Smack dab in the center of a city? Are you painting? Writing? Hitting a golf ball? Indulging your grandkids? Whatever you envision, ITP shouldn't stand in your way. Michael Tarantino, MD, who provides comprehensive care to people with ITP at the Bleeding and Clotting Disorders Institute in Peoria, IL, says these tips can help you enjoy healthy, active days well into the future.

- **Get your care from an ITP expert you trust.**

With a healthcare provider who has in-depth knowledge of ITP, you can feel assured you're getting the latest info and that you have access to cutting-edge research and new therapies.

How to do that? Ask your primary care provider for a referral, reach out to other people who have ITP or log on to pdsa.org to find an ITP expert

Curb stress!

Focus on only one or two doable priorities each day, rather than an overwhelming list. Think: What is it I most want accomplished by the time I'm getting into bed tonight?

near you. Ask any healthcare provider you meet with about their experience in treating ITP.

- **Focus on preventive care.**

That way, you can avoid other health concerns that might require treatment, including surgery, and increase your bleeding risks as a result, Dr. Tarantino explains.

How to do that? Make the connection between good health habits and reducing your bleeding risks. For example, good dental hygiene (that's twice-a-day brushing and flossing, plus regular dental checkups) makes it less likely you'll need procedures like root canals and extractions that could result in bleeding.

- **Don't do things that increase your risk for bleeding.**

Be cautious about the physical activities you engage in, Dr. Tarantino urges. Avoid working in dangerous environments, and use proper safety precautions in your work or your sport.

with ITP

How to do that? Okay, you know that with ITP, you shouldn't take up boxing. But there are commonsense rules that apply to everyone. For example, wash sharp knives separately—don't let them get lost in soapy dishwasher. (See other safety tips on page 27.)

- **Make smart choices during stressful periods.**

The economy, job loss, a household crisis—any bad situation can drive you to crutches such as smoking, drinking, eating poorly or overeating, says Dr. Tarantino. And those can be even more problematic if you have ITP. (For one, alcohol can thin your blood!)

How to do that? Set up your bedroom for sound sleep. Why? Feeling well rested can help you think more clearly—and that leads to picking salmon over a cheeseburger, or a walk over snacking in front of the TV. So make sure your bedding is comfortable and that your bedroom is cool, quiet, clean, dark and allergen-free. 🛏

No grill? No problem!

Broil the fish in your oven, turning once, about 10 minutes or until done.

**Nutrition facts
(per serving)**

Calories 190, fat 6 g
(saturated fat 3.5 g),
cholesterol 75 mg, pro-
tein 29 g, carbohydrates
6 g, fiber 1 g, sodium
130 mg, sugars 4 g

Fresh, delicious—and ENERGIZING!

**WEB
EXTRA!**
For more recipes
go to Guide2ITP.com/recipes

All that summer fun stealing a little of your get up and go? Get it back with this delicious dish. The grilled halibut skewers supply lean protein, which boosts brain chemicals that keep you alert and focused. And the salsa is a great way to sneak in some free radical-fighting antioxidants.

Thai-Style Halibut on Lemongrass Skewers

Makes 6 servings

12 8-inch fresh lemongrass stalks or flat bamboo skewers, soaked for at least 30 minutes

Green Curry

Marinade

- 1 can (14 oz.) coconut milk (regular or light)
- 2 tsp finely grated lime zest
- 2 Tbsp freshly squeezed lime juice
- 1 Tbsp Thai green curry paste
- 2 lb skinless halibut fillet, cut into 3-inch pieces
- Golden Papaya Salsa (see recipe, right)

Prepare the marinade:

In a bowl, whisk together coconut milk, lime zest, lime juice and curry paste. Place fish in a large sealable plastic bag and pour in marinade. Seal bag, toss to coat and refrigerate for at least 30 minutes or up to 8 hours, tossing occasionally.

Meanwhile, prepare a medium-hot fire in your grill. Remove fish from marinade, discard marinade and thread onto lemongrass stalks, leaving space between pieces.

Grill for 10 minutes per inch (2.5 cm) of thickness, turning once, until fish is opaque and flakes easily with a fork. Serve with Golden Papaya Salsa.

Golden Papaya Salsa

Makes about 2 cups

- 2 cups chopped papaya or mango
- 1 tsp grated lime zest
- 2 tsp freshly squeezed lime juice
- 1 tsp hot pepper flakes

In a bowl, combine papaya, lime zest, lime juice and hot pepper flakes. Serve immediately or cover and refrigerate for up to 8 hours.



“Sometimes you just need to talk to someone who really gets it.”

Why ITP support groups work

“Having ITP can be very isolating because you rarely come across people who know how you feel emotionally and physically,” says Caroline Kruse, executive director of the Platelet Disorder Support Association (PDSA). Joining an ITP online community or support group is a great way to find others who understand.

Make an ITP connection

through PDSA: PDSA is a nonprofit organization dedicated to enhancing the lives of people with ITP and other platelet disorders through education, advocacy, research and support.

Meet someone in your area:

Join one of PDSA’s 34 regional ITP groups to talk face-to-face to other people like you.

Teleconference: You can gain a fresh perspective via bimonthly calls with other parents of children who have ITP.

Visit PDSA.org: Communicate with 2,300+ others through PDSA’s online discussion groups.



- **WEBSITE**
200 + pages of information
- **BOOKLETS**
14 FREE booklets (including Spanish and French versions)
- **PUBLICATIONS**
Two quarterly newsletters and a monthly e-newsletter
- **PATIENT SUPPORT & REFERRAL SERVICE**
Answering more than 1,000 calls/emails per year
- **NATIONAL ITP CONFERENCE**
Over 200 attendees each year
- **NATIONAL WALK/RUN**
Pump It Up for Platelets! for a world free of ITP
- **NATIONAL ITP AWARENESS MONTH**
Sport Purple for Platelets Day on the last Friday of September

“As a mother, I just want to feel like I am making the right decision. Thank you so much for what you do and the support PDSA gives so many of us.” ~ Ginny



pdsa.org