“ITP can’t keep me on the sidelines!”

When ITP forced Chris Jordan to give up some of the sports he loved, he found others that keep him active and having fun.
PATIENT GUIDE TO ITP
A low blood platelet disorder

Take control of your ITP symptoms today with our free app

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“Decide that you are in control—and that you’re going to find an ITP treatment that works. It’s empowering!” says Chris Jordan, with his dog, Bailey.
low levels of platelets, cells that play a role in blood clotting. Normally, platelets are made in the bone marrow and enter the bloodstream. In seven to 10 days, they are filtered out by the spleen and to a lesser extent by the liver. But in a person with ITP, platelets are destroyed by the immune system, causing platelet counts to drop below the normal level of 150,000 to 400,000/microliter of blood. (See “Understanding your platelet count” on p. 7.) What’s more, many people with ITP also fail to produce enough platelets in the first place.

Why is it a problem?
With platelet counts so low, your blood struggles to form clots, leading to bruises and bleeding. The lower your platelet count, the more symptoms you may have. Besides bruises, you may notice tiny reddish-purple spots (called petechiae) or larger purplish discolorations (called

No doubt, finding out you have ITP can be disconcerting. For starters, it’s probably the first time you’ve ever heard of the disease. And then there are all the questions:

What’s wrong with my blood?
Will my life ever get back to normal?
Is there a cure? Will I be okay?

Well, take a deep breath, get comfortable and spend some time with this guide, which has the info you need from experts and people like you. People, for example, like Chris Jordan (p. 12). This young sports enthusiast feared ITP would keep him from enjoying the hobbies he loved, yet today he’s as active as ever! And nine-year-old Cayden Krueger (p. 20), who agrees that with a great care team and lots of support, you can have fun while living with ITP.

What is ITP?
ITP, or immune thrombocytopenia, is an autoimmune disease that results in low levels of platelets, cells that play a role in blood clotting.

Normally, platelets are made in the bone marrow and enter the bloodstream. In seven to 10 days, they are filtered out by the spleen and to a lesser extent by the liver. But in a person with ITP, platelets are destroyed by the immune system, causing platelet counts to drop below the normal level of 150,000 to 400,000/microliter of blood. (See “Understanding your platelet count” on p. 7.) What’s more, many people with ITP also fail to produce enough platelets in the first place.

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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. What’s considered a “safe” platelet count can vary. Ask your doctor about the healthiest count for you.

**What your platelet count means**

<table>
<thead>
<tr>
<th>Platelet Count</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>150,000-400,000</td>
<td>Normal</td>
</tr>
<tr>
<td>100,000-149,999</td>
<td>Rarely a risk for bleeding or a need for monitoring by your doctor.</td>
</tr>
<tr>
<td>50,000-99,999</td>
<td>Rarely a risk for bleeding. May require infrequent monitoring by your doctor; rarely requires treatment.</td>
</tr>
<tr>
<td>30,000-49,999</td>
<td>Increased risk of minor bleeding or bruising. May require closer monitoring and treatment for high-risk bleeding situations (e.g., surgery, traumatic injury, contact sports).</td>
</tr>
<tr>
<td>10,000-29,999</td>
<td>Increased risk of minor/moderate bleeding; very low risk of more serious bleeding. Requires close monitoring and, most likely, treatment.</td>
</tr>
<tr>
<td>Fewer than 10,000</td>
<td>Your ITP is serious, and you’re at high risk for spontaneous bleeding. Treatment and possibly even hospitalization may be necessary.</td>
</tr>
</tbody>
</table>

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

- I've also been having:
  - Nosebleeds
  - Bleeding gums
  - Blood in my urine or stool
  - Heavy menstrual bleeding
  - Prolonged bleeding from cuts
  - Coughing up blood clots
  - Bleeding over the white of my eye

**Ecchymoses**, similar to bruises) on your skin. Nosebleeds, bleeding gums and heavy menstrual bleeding may also be an issue, as well as fatigue and anxiety.

**Who gets ITP?**

ITP can strike at any age and has been thought to affect more women than men. However, recent studies suggest it may occur as often in men.

**How is it diagnosed?**

Your healthcare provider must rule out other causes of a low platelet count, such as infection. To do that, they will review your medical history, conduct a physical exam and order blood tests. They will also observe how you respond to different treatments.

**How long does it last?**

In adults, most cases are either persistent (lasting six to 12 months) or chronic (lasting more than a year), while children are more likely to recover quickly. Fortunately, today’s treatments can boost your platelet count and restore your health. But it can take time to find the right treatment (see p. 8 to learn about your options), so it’s important to work with your healthcare team and be patient. After all, the payoff—peace of mind and a greater sense of well-being—is worth it!

Be patient. It can take time to find the treatment that brings you freedom from worry.

in the know
Platelet growth factor therapy is helping adults and children with ITP, too!

Treatments that slow platelet destruction are one way to keep your platelets at a healthy level—but they don’t work in every person. Fortunately, there’s an alternative: a platelet growth factor, or TPO-receptor agonist. (TPO stands for thrombopoietin, a protein that stimulates the bone marrow to produce platelets.) Unlike other ITP treatments, TPO therapy actually boosts production of platelets. TPO therapy may also help some children. They qualify if they are at least one year old, have had ITP for at least six months, and medications and/or splenectomy haven’t worked well enough. For little ones who can’t swallow pills, an injectable form newly approved for children may be an option.

Know your treatment options

Once you’ve been diagnosed with ITP, your hematologist will take a look at your symptoms. If you’re experiencing only mild bruising and petechiae, they may simply observe you for a while. If your symptoms are more severe, they may recommend prompt treatment to raise your platelet counts. To do that, they may prescribe a steroid medication—usually prednisone—to suppress your immune system. They may also recommend IVIg or anti-D immunoglobulin, blood products that can raise platelet levels for a short time.

If these first-line treatments fail or your ITP persists and you continue to require regular treatment, your doctor may recommend one or more of the following (not listed in order of preference or recommendation):

**Platelet growth factors**

Instead of blocking platelet destruction, this class of medicine boosts platelet production. If a particular dose doesn’t seem effective, a higher dose may do the trick. (See box, right, bottom.)

**Splenectomy**

If you have chronic ITP, your hematologist may recommend that you have your spleen removed. (Surgery results in lasting higher platelet counts about 66% of the time. Although this can frequently be done laparoscopically, splenectomy is a serious procedure and works better in those under age 60.) Ultimately, how well you respond to treatment depends on many factors, including your age, platelet count and bleeding history. It’s common to try various approaches. Work with your doctor to find the one that’s best for you. ♻️

**Anti-CD20 monoclonal antibodies**

These disable blood cells that make antibodies and change specific immune system cells.

**Immune-suppressing drugs**

While these drugs are often used to suppress the immune system in transplant patients, they may modestly reduce the immune process in people with ITP.

Your ITP healthcare team

These professionals can help with your ITP:

- **Hematologist**: Doctor who diagnoses and treats ITP and other blood diseases.
- **Primary care provider**: Medical professional who can obtain platelet counts, prescribe meds and refer a specialist.
- **Nurse/nurse practitioner (NP)/physician assistant (PA)**: like your doctor, serves as your advocate and educator.
- **Social worker**: helps you cope with any ITP-related emotional challenges you may have.
- **Infusion nurse**: an RN who administers medication intravenously.

Report your symptoms!

Bruising? Tired a lot? Tell your healthcare provider!
# How medication can help

<table>
<thead>
<tr>
<th>Medication</th>
<th>How it's administered</th>
<th>How it works</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIRST LINE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corticosteroid</td>
<td>IV infusion, pill</td>
<td>Raises platelet count by suppressing the immune system</td>
</tr>
<tr>
<td>Intravenous immunoglobulin-IVIg</td>
<td>IV infusion</td>
<td>Blocks destruction of platelets in the spleen and liver</td>
</tr>
<tr>
<td>Anti-D immunoglobulin</td>
<td>IV infusion</td>
<td>Blocks destruction of platelets in the spleen and liver</td>
</tr>
<tr>
<td><strong>SECOND LINE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Platelet growth factor</td>
<td>Injection, pill</td>
<td>Stimulates bone marrow to produce more platelets</td>
</tr>
<tr>
<td>Anti-CD20 monoclonal antibody</td>
<td>IV infusion</td>
<td>Disables and changes specific immune system cells, reducing antibody production and boosting platelet count</td>
</tr>
<tr>
<td>Immunosuppressive medication</td>
<td>IV infusion, pill</td>
<td>Disables parts of the immune system and raises platelet count</td>
</tr>
</tbody>
</table>

## How well is your treatment working?

Use this worksheet to track your platelet counts.

Date my treatment began: __________________

Starting platelet count: __________________

<table>
<thead>
<tr>
<th>Date of blood test</th>
<th>100,000+</th>
<th>90,000</th>
<th>80,000</th>
<th>70,000</th>
<th>60,000</th>
<th>50,000</th>
<th>40,000</th>
<th>30,000</th>
<th>20,000</th>
<th>10,000</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>PER MICROLITER OF BLOOD</td>
<td></td>
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</tbody>
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**PER MICROLITER OF BLOOD**

**TRACK YOUR PLATELET COUNT**

**you & your healthcare team**

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**THANK YOU**

This document is intended for educational and informational purposes only and should not be used as a substitute for professional medical advice. You should always consult with your healthcare provider before making any treatment decisions.
“I took charge of my ITP!”

Chris Jordan got better control of his health—and found greater peace of mind—when he started partnering with his doctor and embracing his treatment options. —BY KATHLEEN ENGEL

At 27, Chris Jordan likes to stay as active as his schedule permits. When he’s not at his marketing job at a mortgage company (he commutes from his Philadelphia home to Mt. Laurel, NJ), he’s likely either hiking, paddle boarding, golfing or boating. “I’ve found the more physically active I am, the stronger my platelet counts have been and the more stable they are,” says Chris, who was diagnosed with ITP 12 years ago. Going out and doing something—whether it’s getting in a workout or taking a walk—alleviates fatigue and gives him a mental boost, too. And the reason he can manage it all? A great doctor! “I’m blessed to be working with an ITP specialist who wants to see me thrive!”

“ITP came from out of the blue”
Chris didn’t find out he had ITP until a high school physical (he needed one to play football and hockey) revealed his platelets were low. That’s when his doctor suggested he see an ITP specialist in New York City.

At first, Chris used a low dose of a medication only during hockey and football season, with his platelets remaining stable during the off seasons. But after a few years, the strategy stopped working, and Chris started taking steroids and had IVIG. His parents rallied around him. “My mother gave herself a masters degree in ITP and platelets,” he jokes. “She’d track my counts on a spreadsheet and had binders of research material.”

“That anxiety and fear—they don’t help. And they make it harder to be receptive to what the doctor is telling you,” he says. “I was always questioning what my doctors were saying.”

In fact, he once even stopped treatment against his doctor’s advice, only to land in the ER when his gums wouldn’t stop bleeding. “The ER doctor recommended a splenectomy,” he recalls. “That’s when everything came crashing down. It’s when I realized I hadn’t been listening to my doctor, and that if I was going to keep doing that, I’d never get better. I realized my crashes were avoidable!”

“A new attitude—and a new treatment—are working!”
Chris began paying attention to his care team—his doctor, nurse practitioner and physician assistant. “I made sure I was honest with them and I began to trust that they were not going to do anything that would put me in danger.”

His new approach has paid off. These days, Chris says he’s doing well. He participated in a trial that helped determine his optimal dose of an ITP medication. (He feels best with platelet counts above 75,000.) Since his old ITP specialist stopped seeing patients, he now works with a new one. “Occasionally, I’ll notice petechiae or my gums will bleed when I brush or floss, but I’ve seen a vast improvement in my health! And I went from being terrified to understanding that ITP is serious, but you can take care of it!”
“You can thrive with ITP, too”

It’s taken perseverance for Chris to find what worked for him. Here are his tips for thriving with ITP. Ask your doctor if they might work for you, too:

**Find a doctor you trust.** When Chris was forced to admit that he didn’t have all the answers to his ITP, he started listening more closely to his doctor. “You want to make sure you have a good rapport with your doctor and that you’re comfortable enough with them to open up,” he says.

**Work with an ITP specialist.** Chris was 15 when he began making the nearly one-hour trip from his home to see an ITP specialist. “It’s a good idea to see a specialist, even if it means traveling just once a year to see them. Find a local doctor who’s willing to collaborate with them.”

**Connect with the Platelet Disorder Support Association (PDSA).** “Try to make it to PDSA’s annual conference and sign up for the newsletter,” says Chris. “I didn’t want to talk about ITP when I was younger,” he says. These days, he realizes what a difference connecting with someone who has ITP can make. And so he offers his email “for anyone who’d like to reach out to me”: CJJ911@gmail.com.

**Take charge of your health.** “It’s easy to let ITP control you,” says Chris, who used to get pretty discouraged when his platelets crashed. “I’d think, I’ll never find a treatment and I’ll just have to be a hermit and deal with it. But that mindset didn’t help. If you can decide you’re in control and that you’re going to find a treatment that works, it’s an empowering feeling!”

**Find people to lean on.** “There’s nothing shameful about not fighting ITP alone,” says Chris, who’s grateful to his own strong support team, which includes his care team, his parents, friends—and, yes, his loyal pup, Bailey. “I’ve been lucky. My mother was at every doctor’s appointment, even into my twenties! And it really helped [after a platelet crash] when I finally felt I could get out of the house and do something with my friends—they never skipped a beat!”

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**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. How often should I get my platelet count checked? ____________________________
4. What are my treatment options?____________________________________________
5. What effect will different therapies have on my platelet count? ____________________________
6. Which treatment do you recommend? ________________________________________
7. When will I know if my treatment is working? ____________________________
8. If one dosage doesn’t work, can I try another? ____________________________
9. Are there side effects I should tell you or my infusion nurse about immediately? ____________________________
10. Are there any lifestyle changes I should make? ____________________________
11. When should I come back for a checkup? ____________________________

**TIP:** Talk about your top concerns at the beginning of your checkup.
Nplate® is a once-weekly injection proven to boost and sustain platelets to lower the risk of bleeding, so there may be one less thing to keep you from doing what you love.

Could Nplate® help you? Ask your doctor.

Nplate® restores platelet stability for 8 out of 10 adult patients. Also, within 1-3 weeks, the majority of patients on Nplate® reached at least 50,000 platelets per microliter. This is a level thought to help reduce the risk of bleeding.

*Based on overall platelet response

How will I receive Nplate®?

Nplate® is given under the skin (subcutaneous injection) one time each week by your healthcare provider. Your healthcare provider will check your platelet count every week and change your dose of Nplate® as needed. This will continue until your healthcare provider decides that your dose of Nplate® can stay the same. After that, you will need to get blood tests every month. When you stop receiving Nplate®, you will need blood tests for at least 2 weeks to check if your platelet count drops too low.

Pregnancy Surveillance Program: Women who become pregnant during Nplate® treatment are encouraged to enroll in Amgen’s Pregnancy Surveillance Program. The purpose of this program is to collect safety information about the health of you and your baby. Contact the program as soon as you become aware of the pregnancy, or ask your healthcare provider to contact the program for you. You or your healthcare provider can get information and enroll in the program by calling 1-800-77-ANGEN (1-800-772-6436). Please see Prescribing Information and Medication Guide for more information about Nplate® on Nplate.com.

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What is Nplate?
Nplate can cause serious side effects, including:
• Worsening of a precancerous blood condition to a blood cancer (leukemia). Nplate is not for use in people with a precancerous condition called myelodysplastic syndromes (MDS), or for any condition other than chronic (lasting a long time) immune thrombocytopenia (ITP). If you have MDS and receive Nplate, your MDS condition may worsen and become an acute leukemia. If MDS worsens to become acute leukemia you may die sooner from the acute leukemia.
• Higher risk for blood clots.
  ° You may have a higher risk of getting a blood clot if your platelet count becomes high during high treatment with Nplate. You may have severe complications or die from some forms of blood clots, such as clots that spread to the lungs or that cause heart attacks or strokes.
  ° If you have a chronic liver disease, you may get blood clots in the veins of your liver. This may affect your liver function.

Your healthcare provider will closely monitor your Nplate dose and blood tests, including platelet counts during treatment.
• Injection of too much Nplate may cause a dangerous increase in your blood platelet count and serious side effects.
• Your healthcare provider may change your dose or stop Nplate, depending on the change in your blood platelet count. You must have blood platelet counts done before you start, during, and after Nplate therapy is stopped.

See “What are the possible side effects of Nplate?” for other side effects of Nplate.

What is Nplate?
Nplate is a prescription medicine used to treat low blood platelet counts (thrombocytopenia) in:
• adults with chronic immune thrombocytopenia (ITP) when certain medicines or surgery to remove your spleen have not worked well enough.
• children 1 year of age and older with ITP for at least 6 months when certain medicines or surgery to remove your spleen, have not worked well enough.
• Nplate is not for use in people with a precancerous condition called myelodysplastic syndrome (MDS), or low platelet count caused by any condition other than chronic (lasting a long time) immune thrombocytopenia (ITP).

What should I avoid while receiving Nplate?
Avoid situations that may increase your risk of bleeding, such as missing a scheduled dose of Nplate. You should schedule your next dose as soon as possible and call your healthcare provider.

What are the possible side effects of Nplate?
Nplate may cause serious side effects. See “What is the most important information I should know about Nplate?”

The most common side effects of NPLATE in adults include:
• headache
• joint pain
• dizziness
• trouble sleeping
• muscle weakness or weakness
• pain in the arms and legs
• stomach (abdomen) pain
• shoulder pain
• indigestion
• ringing or numbness in hands and feet

How will I receive Nplate?
Before you receive Nplate you should first talk with your healthcare provider and understand the benefits and risks of Nplate.
• Nplate is given under the skin (subcutaneous injection) one time each week by your healthcare provider.
• Your healthcare provider will check your platelet count every week and change your dose of Nplate as needed. This will continue until your healthcare provider decides that your dose of Nplate can stay the same. After that, you will need to get blood tests every month. When you stop receiving Nplate, you will need blood tests for at least 2 weeks to check if your platelet count drops too low.
• Tell your healthcare provider about any bruising or bleeding that occurs during treatment with Nplate.
• If you miss a scheduled dose of Nplate, call your healthcare provider to schedule your next dose as soon as possible.

How will I receive Nplate?
Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal products. Know the medicines you take. Keep a list of them and show it to your healthcare provider or pharmacist when you get a new medicine.

What is the most important information I should know about Nplate?
Your healthcare provider may change your dose or stop treatment.
• Your healthcare provider will check your platelet count about 50,000 per microliter in order to lower the risk for bleeding. Nplate is not used to make your platelet count normal.
• It is not known if Nplate is safe and effective in children under the age of 1.

Before receiving Nplate, tell your healthcare provider about all of your medical conditions, including if you:
• have had surgery to remove your spleen (splenectomy)
• have a bone marrow problem, including a blood cancer or MDS
• have had a blood clot
• have chronic liver disease
• have bleeding problems
• are pregnant or plan to become pregnant. Nplate may harm your unborn baby. Tell your healthcare provider if you become pregnant or think you may be pregnant during treatment with Nplate.

Pregnancy Surveillance Program: Women who become pregnant during Nplate treatment are encouraged to enroll in Amgen’s Pregnancy Surveillance Program. The purpose of this program is to collect safety information about the health of you and your baby. Contact the program as soon as you become aware of the pregnancy, or ask your healthcare provider to contact the program for you. You or your healthcare provider can get information and enroll in the program by calling 1-800-77-AMGEN (1-800-772-6436).
• are breastfeeding or plan to breastfeed. Nplate may pass into your breast milk and harm your baby. Do not breastfeed during treatment with Nplate and for 2 weeks after the last dose.

What are the ingredients in Nplate?
Active ingredient: romiplostim
Inactive ingredients: L-histidine, mannitol, polysorbate 20, sucrose, and hydrochloric acid
For three years, Cayden Krueger from Beloit, WI, has been living with ITP. And these days, it’s not slowing him down. He’s learning some wrestling moves, swimming at the Y and hoping to start football next fall—as long as his platelets are at a healthy level. “It’s okay to live with ITP,” says Cayden. “You can still have fun!” What’s behind Cayden’s upbeat attitude? A mom and dad who promise, “You can live with ITP and still lead a normal life!”

“ITP? What is that?”

“Cayden wants to be the next [Green Bay Packers quarterback] Aaron Rodgers,” says Jenni, Cayden’s mom. “We tell him, ‘You can be. It’s going to be okay!’”

“In time, Cayden’s doctor put him on a treatment that has effectively kept his platelets at a good level and, these days, he has adjusted to the regimen. “Cayden will tell people, ‘I have ITP, but it doesn’t have me!’” says Jenni. He gets his platelets checked every 2-2 ½ months and sees his doctor regularly. “He doesn’t flinch when he’s getting his treatment,” says Jenni. “He’s a champ! When his platelets are up, he can climb a tree, ride a bike, whatever. When they’re down, he gets fatigued. He also gets defiant. His doctor told me, ‘You’re not the first parent I’ve heard that from!’”

But no amount of attitude from Cayden can diminish Jenni’s pride in him: “We’ve done two Pump It Up for Platelets walk-fundraisers for PDSA,” she says. “Cayden gets the word out about them. He’s the one who reaches out to companies and asks for donations. He’s the one who goes into local businesses and asks them to put up posters.”

Come September—national ITP awareness month—he wears a different purple shirt each day that matches the purple Mohawk he sports from July through September. Cayden explains ITP to his friends and classmates this way: “I have this bleeding disorder where I don’t have enough platelets in my blood so I can’t hit my head. To the parents of children with ITP, he’d like you to know: ‘Your child will be just fine. Just make sure they have their platelets checked, like the doctor says. If they are high enough, they can still be in sports! It’s perfect!’”
Mom’s wisdom: “How I keep Cayden happy and healthy—despite ITP!”

Jenni’s learned a few things after three years of managing Cayden’s ITP. Here are a few of the strategies that have helped:

1. Keep your child busy. When low platelets kept Cayden from participating in football last year, Jenni found other things for him to do. “We didn’t want Cayden to sit on the sidelines,” she says. So she signed him up for swimming (no diving) and wrestling (no contact—but he gets to run around the mats with the other kids and learn the moves). Plus, he’s got three siblings—Cody, Casie and Cora—who keep him busy.

2. Keep teachers and coaches in the loop. Jenni finds peace of mind knowing the adults who watch over Cayden are informed of his health status. Says Jenni: “I do a weekly update. I’ll send an email: Cayden is doing fine. He can play.”

3. Stay on top of their ITP—within reason. “Six months ago, Bob and I realized we were letting ITP run our lives,” says Jenni, who works in the health office of a local high school. “We were constantly, ‘Let me look in your mouth, let me look at your legs, let me look at your arms… We don’t do that any more. Once a week, we’ll inspect Cayden—that’s it.”

4. Connect with others. By reaching out to the Platelet Disorder Support Association (PDSA), Jenni found comfort and answers to her questions. “It has 100% saved our lives! I can call PDSA when I want information or, after hours, find it on their site.” She is also in regular contact with parent friends on PDSA’s Facebook page.

5. Make treatment days fun. After Cayden gets treated, “We’ll go right out to eat, and Cayden gets to pick the restaurant,” says Jenni. Time and weather permitting, they might also visit the local zoo. “We make the day more fun!”

6. Spell out good safety rules. After bumping his head while visiting friends with his big brother, Cayden experienced a brain bleed and was hospitalized and given emergency treatment. Yet Jenni found out about the bump only after Cayden came home, developed purpura and began vomiting. While everything turned out okay in the end, Jenni and Bob talked to Cayden and his two older siblings, Cody and Casie: “If this ever happens again, we need to know,” they cautioned their children. “No one’s in trouble, but we need to be aware.”

Introducing the new & improved ITP Monitor

TAKE CONTROL OF YOUR ITP SYMPTOMS TODAY WITH OUR FREE APP!

This simple-to-use, intuitive and streamlined program can help you...

• Track your platelet counts, appointments and other events
• Keep track of related symptoms, like bruising, bleeding and hematomas
• Use photographs to track symptoms
• Log your ability to function
• Get personalized reports, including insights on your symptoms, medication use and triggers to share with your healthcare team
• Connect with other patients anonymously

Text ITPMONITOR to 41411 to download

Download on the App Store

Google Play

HealthMonitor®
Anxious about ITP?
Here’s help!

Knowing that, without warning, your blood may be unable to clot, leading to serious bruising and bleeding, can set anyone’s nerves on edge. So it’s no surprise that people with ITP may experience periods of fear and mental distress, according to research published in the journal Current Medical Research and Opinion. To keep calm during a platelet crash or when symptoms appear (and all those times in between), answer the questions below and try the tips that follow each one. Also: Fill out the worksheet, right, and review with your doctor.

1 Do I make myself anxious just thinking about my ITP?
The anticipatory fear and “what if” questions—When will my platelets crash again? Is something bad going to happen to me?—may combine with other medical factors to trigger an ITP episode.

If yes, try this:
• Do your part. “Eating a healthy diet, staying compliant with your treatment plan, not abusing alcohol, getting adequate sleep—knowing you’re doing whatever you can to take care of your body can help keep anxiety at bay,” says Julia Samton, MD, a psychiatrist practicing in New York City.

• Create a low-stress lifestyle. “Try to achieve a balanced life with work, play, time with loved ones, exercise—a life driven by your personal values,” says Dr. Samton, who also recommends 10 to 20 minutes of meditation a day. Since it can be hard to reason with yourself when you are having symptoms, being able to ground and center yourself can help to separate your emotions from what’s going on with your platelets.

• Have a plan. If you haven’t already, get instructions from your doctor about what you should do if you experience signs of low platelets. Just having a plan in place can make you feel more in control of your health.

2 Do I become anxious the moment I see petechiae?
People with ITP who struggle with anxiety may find they have more frequent or more severe ITP symptoms and a poorer quality of life.

If yes, try this:
• Breathe! When you notice you’re experiencing signs of anxiety, such as racing thoughts, irritability or excessive worry, “inhale deeply, silently counting to five,” says Dr. Samton. “Hold your breath for two counts. Exhale slowly, for five to eight counts.” By slowing your breathing rate and pattern, you can stimulate the body’s relaxation response.

• Bring yourself back to the present moment. If your mind starts racing, reassure yourself: You are going to be okay. Put things in perspective: This is my ITP. I’m going to breathe through it/distract myself until I can reach my care team (or whatever your doctor has instructed you to do).”

Is ITP taking an emotional toll?
Although ITP targets your platelets first and foremost, it can take an emotional toll, too. In fact, a study published in the International Journal of Hematology-Oncology and Stem Cell Research showed that people with ITP who experienced recurrent bleeding and hospitalizations felt a loss of control and were likely to have severe perceived stress, depression and a poorer quality of life. Fill out the worksheet, right, and review it with your ITP care team. They can help you find ways to feel calmer, more confident and more in control of your health.
How is ITP affecting you?

Living with a chronic medical condition like ITP can be challenging. Thankfully, with today’s treatments you have more options and support than ever! Fill out the assessment below and review it with your healthcare provider, so you can rest assured that your treatment plan is the best it can be.

1. I seem to develop ITP symptoms such as petechiae, purpura and nose or gum bleeds when:
   - I get sick
   - I work too much/have job stress
   - I overdo physical activity
   - It's winter/spring/summer/fall (circle which)
   - I have family/relationship problems
   - I have financial stress
   - I take certain medication

2. In the past month, I’ve felt:
   - Fatigued or weak
   - Anxious
   - Down, depressed
   - Unable to sleep
   - Fearful
   - Frustrated
   - Embarrassed
   - Resentful

   
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<tr>
<th>Feeling</th>
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3. I have also been diagnosed with:
   - An immune disorder
   - A blood disorder
   - Skin disease
   - Gastrointestinal disease
   - Thyroid disease
   - Liver disease
   - Infection
   - Osteoporosis
   - Other: ______________________________

4. I am satisfied with:

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<td>The types of exercise I can do</td>
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<td>The diet I’m able to eat</td>
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<td>My social life</td>
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<td>My ability to travel/pursue hobbies</td>
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<td>How often I need my blood tested</td>
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<td>The side effects of my current treatment</td>
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<td>My relationships</td>
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5. I have noticed that the following seem to trigger my ITP:
   - Illness
   - Emotions, such as stress, worry, anger, fear
   - Physical exertion
   - Over-the-counter medications
   - Alcohol
   - Caffeine
   - Smoking
   - Dehydration
   - Other: ______________________________
   - It’s totally random

Visit PDSA.org today!
Move with confidence!
Everyday ways to stay safe on your feet—BY KAREN KLEIMANN

As you know, ITP can make it easy for bruises to show up—and a bump on the head can have severe consequences. In addition to following the treatment regimen your doctor recommends, try these simple lifestyle tips to keep your bones and body strong—so you’re able to live the life you enjoy!

Keep active
Exercise may be the key to decreasing falls and injuries from falls, according to the U.S. Preventive Services Task Force. But with ITP, not all exercises may be right for you. Talk to your healthcare provider about the types of activities you can safely enjoy—things like walking, swimming or riding a stationary bike may be good options. Consider working with a certified personal trainer experienced in helping people with ITP.

Clear the clutter
Store items within reach, but out of the way, so they don’t become a fall or trip hazard. A wall rack can help keep umbrellas, keys, jackets, bags and hats easily accessible while storage ottomans are ideal for holding books, magazines and toys. Keep stairs clear of all clothing and shoes—if this is a hotspot area for items, use a sturdy basket or bin at the top or bottom of the stairs, where it is not within the walking path.

Get a good grip
Wear shoes and slippers with a rubber sole to help prevent falls and slips. Also, use slip-proof mats in your kitchen, hallways, bathrooms and living spaces—even outdoor stairs—to prevent slips and falls.

Ditch distractions
Focus on one thing at a time—paying attention to what you’re doing and where you’re headed can help you stay balanced and aware of tripping hazards. More than half of distracted walking injuries reported happen inside people’s homes, according to the National Safety Council. And avoid playing with your phone when walking! Research has shown that with an increase in cellphone use, the number of injuries has also risen, with one study from Ohio State University showing that pedestrian cellphone-related injuries have more than doubled since 2005.

Light a path
Keep rooms well-lit with an easy-to-reach lamp, or use nightlights to help you see more easily in darker areas. Take your time when letting your eyes adjust to dim lighting, so you don’t trip on furniture or other items in a room.

Get the right support
If you need them, assistive devices like a cane, walker or walking stick can help you move around more easily while minimizing your risk of falls. To feel more comfortable using a mobility aid, make a list of all the things you’d like to do and how the device can help you stay active. Choose one that is easy to store, adjusts to your height and is ergonomically designed for your comfort.

Prep for the weather
Wear weather-appropriate shoes for rainy or snowy days, and walk on even ground away from slippery surfaces. Salt, kitty litter or sand on icy patches can make your walking path safer.

Wipe down damp areas
Spills on floors and rain puddles in the foyer can become slip hazards. Keep walkways safe by storing towels nearby and wet items out of the way. Consider replacing your welcome mats with waterproof rubber ones and using mesh or wire storage bins and baskets in the entryway or mudroom to hold paper and cloth towels and store wet shoes.

Test your vision
Older adults who have visual impairments have nearly double the increased risk of falling, according to a study in Optometry in Practice. You can reduce your risk of falling by staying current on eye exams and being proactive, such as by getting corrective lenses, if needed.

Ease up on chores
Take breaks to minimize stress on your joints and don’t be afraid to ask for help—especially when grocery shopping and traveling. Prioritize your to-do list based on your energy levels and break tasks into smaller pieces so you can tackle them without straining.
Go green for health!

The peppery arugula in this salad is rich in vitamin K, calcium and minerals that promote clotting, while chicken is a lean source of protein that fills you up and provides a steady source of energy.

Apricot and Chicken Salad with Toasted Cumin Vinaigrette
Makes 4 to 6 servings

Toasted Cumin Vinaigrette:
1 Tbsp cumin seeds
2 Tbsp freshly squeezed lemon juice
2 Tbsp brown rice vinegar
1 tsp honey
3/4 tsp sweet paprika
1/4 tsp fine sea salt, plus more to taste
1 1/2 Tbsp finely chopped fresh cilantro leaves
1/4 cup extra-virgin olive oil
Freshly ground black pepper

To make the vinaigrette, in a small frying pan over medium-low heat, toast the cumin seeds until golden and fragrant, about 3 minutes, stirring regularly. Grind the seeds in a spice grinder or mortar and pestle. In a bowl, whisk together the cumin, lemon juice, vinegar, honey, paprika and salt. Gradually whisk in the oil until the vinaigrette is emulsified. Whisk in the cilantro and parsley. Season with pepper.

To make the salad, in the same small frying pan, toast the almonds over medium-low heat, stirring often, until golden and fragrant, about 4 minutes. Set aside to cool.

In a large serving bowl, toss together the chicken, apricots, half of the almonds, and the arugula. Drizzle with 3 to 4 Tbsp of the vinaigrette and toss gently until the vinaigrette is evenly distributed. Garnish with the remaining almonds and season to taste with more salt if desired. Serve with the remaining vinaigrette on the side. Store any leftover vinaigrette in an airtight container in the refrigerator for up to three days.

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Resources you need now!

Are you looking for more information on ITP and other blood disorders? Hoping to connect with others who understand you? Get the answers you want and the support you need by checking out these organizations.

OUR PARTNERS:

The Platelet Disorder Support Association (PDSA) is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support. Patient-founded in 1998 to educate and empower those impacted by immune thrombocytopenia and other rare platelet and bleeding disorders, PDSA is now a powerful force serving and unifying the global ITP community of patients, practitioners, caregivers, advocates and key disease stakeholders. PDSA is committed to building awareness, educating the global community, and providing critical connections and resources that empower patients to take charge of their disease and encourage practitioners to exercise patient-centered medical care. YOU’RE NOT ALONE. Visit www.PDSA.org today!

The Infusion Nurses Society (INS), located in Norwood, MA, is a national nonprofit organization representing infusion nurses and all other clinicians who practice infusion therapy. Since 1973, INS has continued its commitment to bringing innovative new resources and learning opportunities to the wide range of healthcare professionals involved in the specialty practice of infusion therapy. We are dedicated to advancing the delivery of quality infusion therapy to patients, enhancing the specialty through stringent standards of practice and professional ethics, and promoting research and education in the infusion nursing practice. Visit www.ins1.org to learn more.

Immunoglobulin Nursing Society
ig-ns.org

The Daisy Foundation
Daisyfoundation.org

National Organization for Rare Disorders
Rarediseases.org