

A Roadmap for Every Step of the ITP Journey



Shared decision-making tools for patients, caregivers, and medical professionals impacted by Immune Thrombocytopenia (ITP)

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A Roadmap for Every Step of the ITP Journey

Introduction



Your Journey Starts Here

The Platelet Disorder Support Association (PDSA) is proud to present *A Roadmap for Every Step of the ITP Journey*, a shared decision-making toolkit for patients, caregivers, and medical professionals impacted by Immune Thrombocytopenia (ITP). This work was made possible through a collaboration with Novartis under the leadership of Links2Equity.

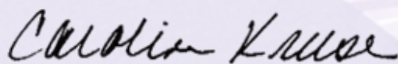
For many people living with immune thrombocytopenia (ITP), the journey to diagnosis is long, confusing, and at times deeply frustrating. I know this not only through my work, but through lived experience. Like many others with ITP, I spent years searching for answers while my symptoms were misunderstood, minimized, or attributed to something else. That experience shaped how I understand this disease and why I believe strongly in the need for people to direct their own care decisions.

ITP is a serious and often unpredictable rare blood disorder. Its symptoms can range widely from person to person and may include both visible and invisible challenges, such as fatigue, brain fog, and emotional strain. That means your experiences won't always show up in lab results, making it hard to feel truly heard.

That is why shared decision-making is fundamental to the successful, compassionate treatment of ITP.

The Platelet Disorder Support Association (PDSA) is the only organization dedicated exclusively to people living with ITP. For decades, we have worked alongside patients, caregivers, clinicians, and researchers to improve awareness, advance education, and ensure that individuals living with ITP have access to trusted information and meaningful support. This toolkit reflects that commitment.

Developed to support better care for ITP, this shared decision-making guide will help you or your loved ones have open conversations about treatment goals and preferences.



Caroline Kruse, President and CEO
Platelet Disorder Support Association (PDSA)



Understanding Your Diagnosis

What is Immune Thrombocytopenia (ITP)?

Immune thrombocytopenia (ITP) is an autoimmune disorder in which the immune system mistakenly targets platelets, leading to increased platelet destruction and, in some people, impaired platelet production. This can lead to a low platelet count. Because platelets help the body stop bleeding, a low platelet count can increase the risk of bleeding and may cause symptoms such as bruising and petechiae (small red or purple spots on the skin).

ITP impacts between 4 and 5 out of every 100,000 children, and 3 and 8 out of every 100,000 adults. Unfortunately, its causes, symptom profiles, and treatment options can vary. This means that living with ITP often involves learning how the condition will affect your unique body and daily life.

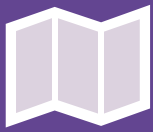
ITP can affect more than platelet counts and bleeding. Roughly half of adults with ITP report fatigue and impairments in mental and emotional health, physical health, and social functioning. These effects can have an important impact on daily life and may not always be reflected by a person's platelet count or bleeding symptoms.

Some people with ITP experience mild symptoms, while others face more serious bleeding risks. In some cases, it appears suddenly and resolves over time. In others, ITP is a chronic condition that requires ongoing monitoring and treatment.

People with ITP face a long path to an accurate diagnosis.

There is currently no definitive test to diagnose ITP, so healthcare practitioners must work to exclude other illnesses before making an ITP diagnosis. It is not uncommon for symptoms to initially be overlooked or mistaken for other conditions.

Understanding the signs of ITP and communicating your experiences clearly with your healthcare provider may help improve your diagnostic experience and ensure you can more fully direct your care plan.



A Roadmap for Every Step of the ITP Journey

Understanding Your Diagnosis

How Does ITP Develop?

In many children, ITP develops a few days or weeks after a viral infection. The infection may have been mild and may have already resolved before the low platelet count is discovered. In rare cases, ITP may occur after certain vaccinations, most notably the measles-mumps-rubella (MMR) vaccine. The risk is very small.

In adults, ITP may occur without an identifiable underlying cause and is then called primary ITP. ITP can also occur as a secondary condition associated with another illness, infection, autoimmune disorder, immune deficiency, certain medications, or, less commonly, an underlying cancer such as lymphoma.

ITP is a diagnosis of exclusion, meaning there is no single test that can definitively diagnose ITP. Doctors consider a person's medical history, medications, physical examination, complete blood count, and blood smear while ruling out other possible causes of a low platelet count. This is why it is important to tell your healthcare provider about recent infections, medications, vaccinations, other medical conditions, and any signs or symptoms you have experienced.

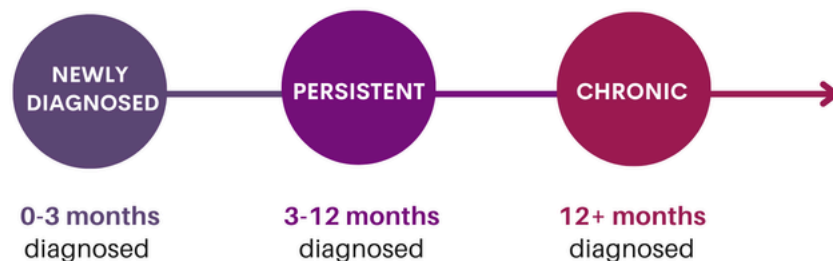
How Long Does ITP Last?

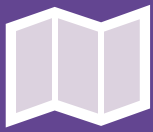
In both children and adults, ITP may be newly diagnosed, persistent, or chronic:

- **Newly diagnosed ITP:** ITP that has been present for less than 3 months
- **Persistent ITP:** ITP that lasts 3 to 12 months
- **Chronic ITP:** ITP that lasts longer than 12 months

Children are more likely than adults to have ITP that resolves on its own, while adults are more likely to develop persistent or chronic ITP.

THE PHASES OF ITP



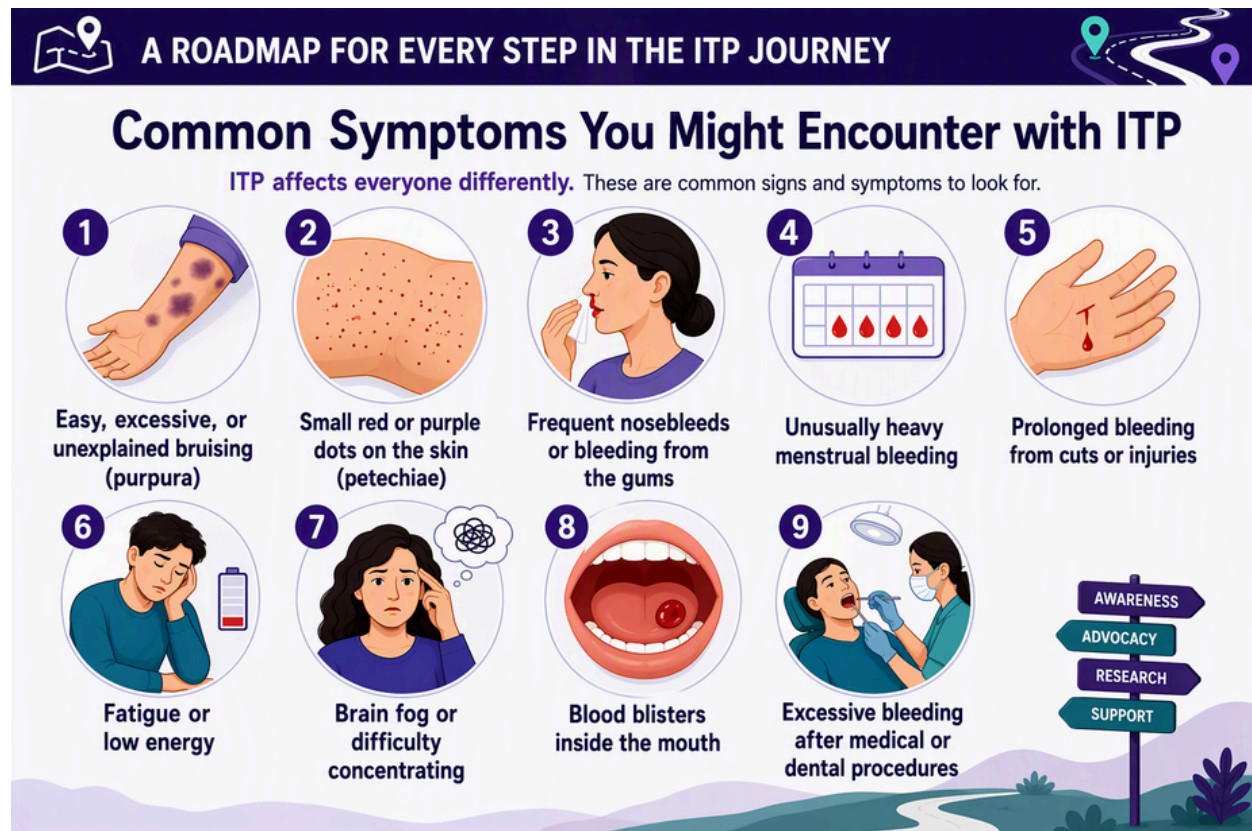


A Roadmap for Every Step of the ITP Journey

Understanding Your Diagnosis

Identifying Your Signs and Symptoms

One of the first steps toward diagnosis is recognizing changes in how your body feels or functions. ITP typically presents with signs that healthcare professionals can observe or measure, such as platelet counts or visible bruising, and symptoms that you may notice, such as fatigue or unusual nosebleeds.



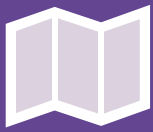
People with ITP experience a mix of visible and invisible symptoms. Fatigue, brain fog, and other quality-of-life concerns may not appear in laboratory results but can still significantly affect daily activities. It is important to track changes in how you feel and share these with your healthcare team to improve their understanding of what is happening in your body.

Platelet Disorder Support Association (PDSA). *Understanding Your Diagnosis*. pdsa.org/understanding-your-diagnosis

Neunert C, Terrell DR, Arnold DM, et al. American Society of Hematology 2019 guidelines for immune thrombocytopenia. *Blood Adv*. 2019;3(23):3829-3866. <https://ashpublications.org/bloodadvances/article/3/23/3829/429213/American-Society-of-Hematology-2019-guidelines-for-immune-thrombocytopenia>

Terrell DR, Beebe LA, Vesely SK, Neas BR, Segal JB, George JN. The incidence of immune thrombocytopenic purpura in children and adults: A critical review of published reports. *Am J Hematol*. 2010;85(3):174-180. <https://doi.org/10.1002/ajh.21616>

National Organization for Rare Disorders (NORD). *Immune thrombocytopenia*. rarediseases.org/rare-diseases/immune-thrombocytopenia



A Roadmap for Every Step of the ITP Journey

Understanding Your Diagnosis



Resources

Understanding ITP in Children and Adults

ITP in Children

pdsa.org/children

Pediatric Treatment Options

pdsa.org/images/PediatricTreatmentGrid.pdf

ITP in Adults

pdsa.org/adults

Adult Treatment Options

pdsa.org/images/AdultTreatmentGrid.pdf

Rest Stop: **Meet ITP Warrior Kaitlyn**

When the exhaustion never ends

“I was a majorette in my university’s marching band, the East Tennessee State University Marching Bucs. After long practices, I would feel unwell, but I brushed it off as just being exhausted. But the exhaustion seemed to never end.

I visited my primary care doctor, complaining of dizziness and numbness, and was referred to a hematologist. It was clear that I was anemic; I was deficient in vitamin B12 and iron. However, my bloodwork revealed more problems, including a platelet count of 30,000.

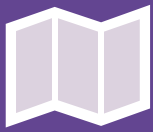
My initial thought was, “Maybe college is just stressing me out,” but that was not the case. My hematologist told me I needed to limit any activity in which I risked getting injured. I had to quit performing as a majorette.

I finally received a diagnosis in April 2022 after a bone marrow biopsy ruled out any cancers or other blood disorders I could have had. From July through September 2022, my platelets remained at a good level.

Then, October came. I went to the hematologist for my monthly checkup and my platelets were low. I may have to resort to another style of treatment. Ultimately, I am staying positive throughout my ITP journey. I won’t let ITP define me and the rest of my college journey.”

Read Kaitlyn’s full story at pdsa.org/itp-warrior-kaitlyn.





A Roadmap for Every Step of the ITP Journey

Understanding Your Diagnosis

New Criteria for the Diagnosis of ITP

As described in a journal article from the American Society of Hematology (ASH), researchers have proposed new criteria for the diagnosis of ITP:

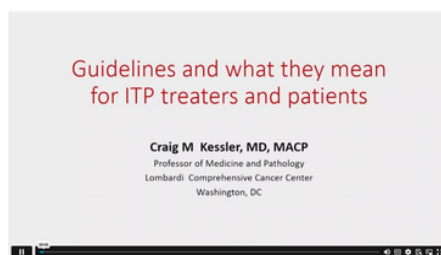
1. All the following
 - Thrombocytopenia ($<100,000/\mu\text{L}$)
 - Absence of anemia (excluding anemia due to bleeding and/or iron deficiency)
 - Normal leukocyte count (but may present with mild abnormal leukocyte count)
 - No morphological evidence of dysplasia in any blood cell type in a blood smear
2. Normal or slightly increased plasma TPO level ($<\text{cutoff}$)
3. Elevated percentage of immature platelet fraction (RP% or IPF%; $>$ upper limit of normal)
4. Absence of other conditions that potentially cause thrombocytopenia including secondary ITP
 - A diagnosis of ITP is made if conditions 1-4 above are all met (ITP)
 - Cases in which criterion 2 or 3 is not met or unavailable are defined as “possible ITP, pITP”. A diagnosis of ITP can be made if the patient is a glycoprotein (GP)-specific platelet-antibody positive, increased GP-specific platelet antibody-producing B cells, or typical clinical course.

Kashiwagi H, Kuwana M, Murata M, et al. Proposal of New Diagnostic Criteria for Primary Immune Thrombocytopenia. *Blood*. 2023;142(Suppl 1):1214. <https://doi.org/10.1182/blood-2023-179165>

ITP Treatment Guidelines: pdsa.org/health-care-provider-resources/hcp-resources#guidelines



Shared-Decision Making Tool: **ITP Guidelines and What They Mean**



Guidelines and What They Mean for ITP Treating
and Patients

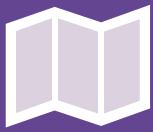
Craig M. Kessler, M.D., MACP,
Professor of Medicine and Pathology,
Lombardi Comprehensive Cancer Center

Video Link: [Guidelines and What They Mean for ITP Treating and Patients](#)



Many rare diseases are first identified through the symptoms people report to their healthcare providers. This is especially common in diseases like ITP, where symptoms can resemble those of other conditions. Tracking and sharing details of your experiences is an important part of getting an accurate diagnosis.

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A Roadmap for Every Step of the ITP Journey

Sharing Your Signs and Symptoms with Your Doctor

First Visit: Questions to Ask Your Doctor

- ☐ Could my symptoms be related to ITP?
- ☐ What tests are needed to confirm a diagnosis?
- ☐ Are there other conditions that might cause these symptoms?
- ☐ Should I see a specialist, such as a hematologist?
- ☐ What are all the treatment options for ITP?
- ☐ What side effects should I expect?
- ☐ How is each treatment administered?
- ☐ How often will I need a treatment and for how long?
- ☐ What will this cost me? Is there any program to help me with that cost?
- ☐ What are our follow-up steps?



Shared Decision-Making Tool: The Science Behind the Diagnosis of ITP



Need help tracking symptoms and talking to your doctor?

Use this list of science-based symptoms to talk with your or your child's medical professional about your condition and what diagnostic tests you should expect.

The Science Behind the Diagnosis of ITP
pdsa.org/images/ScienceBehindDiagnosis.pdf

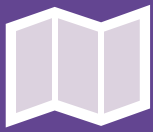
Diagnostic Testing

Unlike some conditions that can be diagnosed with a single test, ITP is often identified through a process of evaluation and elimination. Doctors may perform several tests to understand what is happening in your body and to rule out other conditions with similar symptoms.

Your healthcare provider may describe this as a “diagnosis of exclusion,” in which multiple tests are used to rule out other possible explanations before confirming the ITP diagnosis.

Tests used during your diagnostic journey may include:

- Complete blood count (CBC): Determines a platelet count.
- Peripheral blood smear: Follows a CBC to look at different types of blood cells.



A Roadmap for Every Step of the ITP Journey

Sharing Your Signs and Symptoms with Your Doctor

- Bone marrow tests
- Other blood and urine tests
- Genetic testing

Providers may also review your medical history, medications, and any recent illnesses that could affect platelet counts. Together, tests and your self-reported symptoms are essential to getting an accurate diagnosis and determining the most appropriate treatment.

Rest Stop: **Meet ITP Warrior Dale**

Learning to live with ITP

Since his diagnosis in October 2010, Dale's ITP treatment journal has grown to include watchful waiting, dexamethasone, IVIG, splenectomy, fostamatinib, rituximab, and eltrombopag. In the following years, Dale found success with IVIG in keeping his platelet count up until it began to "lose its punch."



Noticing that the IVIG would get his platelet counts up to around, say 180,000, and then would drop backdown, Dale started a dialogue with his hematologist. His doctor suggested a regular IVIG treatment schedule to avoid unnecessary trips to the lab for bloodwork. This helped normalize life a bit for Dale in terms of work obligations, offering flexibility in scheduling meetings and responsibilities around treatment appointments.

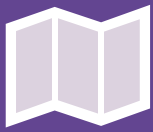
Eventually, scheduling time for IVIG every three to four weeks became quite burdensome. In 2014, Dale's spleen was removed, and it failed. Finally, Dale found relief on a combination of IVIG and a new medication, giving him a chance to stabilize his platelets and improve his quality of life.

"There are days you go through the symptoms and the anxieties and the fatigue. I don't have as much as I did when I was first diagnosed and I've noticed more doctors recognizing the fatigue where they weren't in the beginning."

Dale's advice to others newly diagnosed with ITP? Get involved.

"It's going to be okay - it's not the end of the world. It's something you need to learn how to live with and manage. We're not all the same; there are things we can do, there are things we can't do, but between associations like PDSA and others around the world, you learn very quickly that you're not alone. Welcome to a group that you didn't want to be part of but you're darn glad there's other people here."

Read Dale's full story at pdsa.org/itp-warrior-dale.



A Roadmap for Every Step of the ITP Journey

Sharing Your Signs and Symptoms with Your Doctor

Referrals and Second Opinions

Your primary care provider may refer you to a specialist for further evaluation. Specialists who commonly treat ITP include hematologists, doctors who focus on blood disorders.

Specialists often have additional experience interpreting complex test results and recommending treatment options. Specialists can help you feel more confident in their diagnosis and better prepared for decisions ahead.

It is always okay and appropriate for you to ask for a referral or seek a second opinion. You are in control of your health, and your healthcare team should support you when you want more information.

Second opinions do not mean you distrust your current provider. Instead, they can offer reassurance and provide the information you need to move forward with confidence. Asking questions and advocating for yourself are important parts of shared decision-making.



Resources

Find a Hematologist

Finding the right specialist can sometimes be difficult, depending on where you live and your ability to travel for appointments. PDSA offers a **Find a Hematologist** tool designed to connect you with experts who can confirm or support your diagnostic journey.



Search for ITP specialists near you using the [Find a Hematologist](https://pdsa.org/find-a-hematologist) tool at pdsa.org/find-a-hematologist.



A Roadmap for Every Step of the ITP Journey

Sharing Your Signs and Symptoms with Your Doctor

Managing and Tracking Symptoms After Diagnosis

It's important to continue tracking your symptoms and any concerns after your diagnosis. Keeping this record is an important part of managing ITP because it helps you and your healthcare team track your condition over time. You can also take note of how a treatment impacts your day-to-day.

Some symptoms are easier to measure than others. Platelet counts and bleeding events may be recorded during appointments, while experiences such as fatigue or brain fog may be harder to quantify. Even if a symptom is hard to monitor or describe, you and your care team will benefit from your attempts to track it.

Consider tracking symptoms such as:

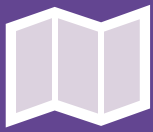
- ☐ Bruising or bleeding episodes
- ☐ Nosebleeds
- ☐ Fatigue levels
- ☐ Headaches
- ☐ Brain fog or concentration challenges
- ☐ Changes in physical activity or stamina
- ☐ Menstrual bleeding patterns
- ☐ Emotional or mental health changes

Platelet Counts and Symptom Burden

Many people living with ITP notice that their symptoms do not always match their lab results. For instance, platelet counts may appear stable, but you might experience worsening fatigue or brain fog. This disconnect can make it difficult to show some providers the extent to which ITP affects your quality of life.

For shared decision-making, your personal experience is just as important as the results of standard tests. Talk with your provider to ensure that both guide their treatment decisions. Doctors may not know what questions to ask about your daily life, so share how symptoms are impacting your work, habits, hobbies, or relationships.

Understanding the difference between laboratory results and lived experience helps you and your providers work together more effectively.



A Roadmap for Every Step of the ITP Journey

Sharing Your Signs and Symptoms with Your Doctor

Managing Fatigue and Tiredness

Fatigue is one of the most common and disruptive symptoms reported by people living with ITP. It can affect concentration, work, relationships, and many daily tasks and activities that others take for granted.

Some people with ITP find that routine can help manage fatigue and tiredness. Options to consider include:

- Maintaining regular meals and hydration
- Building moderate, sustainable physical activity
- Planning around high- and low-energy periods
- Avoiding overexertion on higher-energy days
- Talking with providers about contributing factors such as sleep, treatment effects, or stress

Fatigue is real and can be debilitating. Discuss it openly with your care team to develop a plan to address your fatigue.

Using Data to “Make the Case”

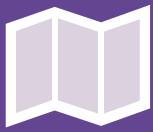
Sometimes, a well-meaning doctor or healthcare provider can downplay the patient’s experience of ITP because their understanding of the disease’s presentation is limited. Research can help persuade your healthcare provider to take your ITP experiences seriously.

The **ITP World Impact Survey (I-WISH)** was designed to help practitioners understand the impact of ITP outside of the doctor’s office by collecting insights from 1,400 people living with ITP.



For example, more than half (66%) of doctors in the survey thought that ITP-related fatigue could reduce a patient’s quality of life. Yet for people living with ITP, fatigue was the most prevalent and most severe symptom that impacted their quality of life. Sharing the survey with your healthcare team may improve their understanding of the impact of fatigue on your day-to-day life.

Kruse C, Kruse A, Watson S, et al. Patients with Immune Thrombocytopenia (ITP) Frequently Experience Severe Fatigue but Is It Under-Recognized By Physicians: Results from the ITP World Impact Survey (I-WISH). *Blood*. 2018;132(Suppl 1):2273.
<https://doi.org/10.1182/blood-2018-99-112378>

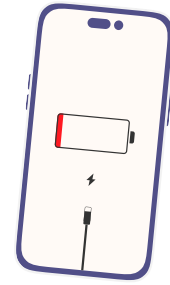


A Roadmap for Every Step of the ITP Journey

Sharing Your Signs and Symptoms with Your Doctor

Talking to Others About Your Fatigue

How do you explain to friends and family members how a disease like ITP can drain your energy or heighten your fatigue?



For people with ITP, it can be helpful to think of your energy like a phone battery. Each day, you start at 100%.

Symptoms, treatments, poor sleep, stress, and the day-to-day demands of living with a chronic illness can all use up your available energy. As a result, your battery may reach 0% much faster than you expect - even during everyday activities such as doing chores, going to a doctor's appointment, or participating in social activities.

For someone living with a chronic illness, even small activities such as getting dressed or brushing their teeth can noticeably drain their battery. Activities that seem simple to others may require significant energy when your battery is already running low.



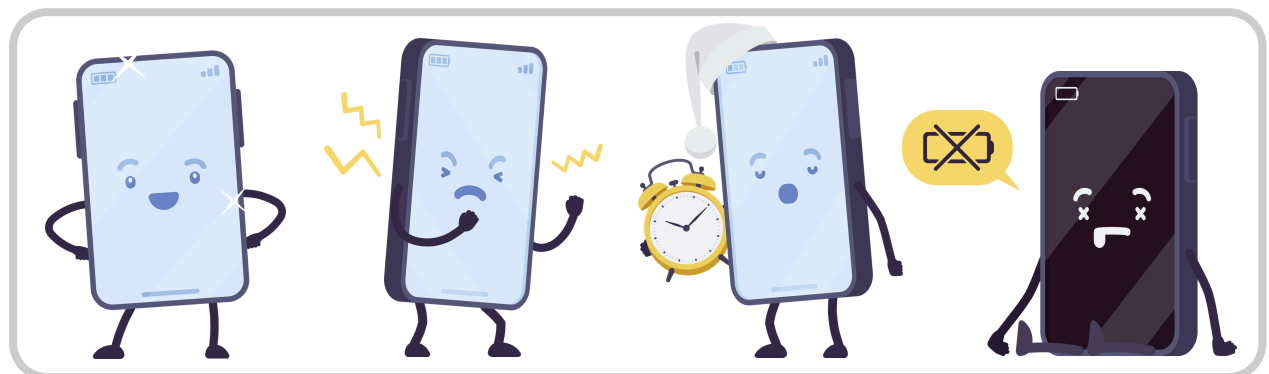
With ITP, some days you might not start at 100%. Your fatigue might mean you're beginning the day at 75% battery, so each symptom gets you down to 0% that much faster.

You can share your battery life to communicate fatigue with your care team, friends, or family:



"I'd love to do that, but my battery feels like it's running on empty." That shorthand can help others understand how severe your fatigue is and respond better to your needs.

Adapted from: Miserandino C, Lymphoma Action. *The Spoon Theory*. lymphoma-action.org.uk/sites/default/files/media/documents/2020-05/Spoon%20theory%20by%20Christine%20Miserandino.pdf





SHARED DECISION-MAKING Discussion

COLLABORATIVE APPROACH

- INSIGHTS**
 - FROM A STUDY DONE WITH THE PATIENT COMMUNITY
 - UNDERSTANDING
 - IMPACTS
 - PATIENTS PERSPECTIVE
- ASK FOR WHAT YOU NEED!**
 - EXPERTISE
 - INFORMATION
 - RESEARCH
 - PHYSICIAN SUPPORT
- involved 3 TIMES MORE WITH A SDM PROCESS**
- IMPACT OF BURDEN OF DISEASE**

OPEN DIALOGUE

- HCP AND TEAM**
 - DIALOGUE ASSISTS WITH COMPREHENSION
 - WOULD BE GREAT IF COORDINATED
- SYMPTOMS**
- GOALS**
- TREATMENT PREFERENCES**
- IMPACT OF BURDEN OF DISEASE**

SHARED DECISION-MAKING LENS

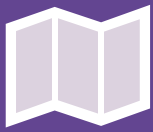
- HOLISTIC APPROACH**
 - CAN BE INSTIG BUT WOULD HAVE A MORE HOLISTIC APPROACH
 - 69% UNDERSTANDING OF IMPACT
 - NUTRITION
 - CONSIDER THE SETTING OF CARE
- QUALITY OF LIFE QUESTIONS**
 - PRACTICING CONNECTION TO PROVIDING
 - DON'T FEEL YOU DON'T NEED THESE TOOLS AS WELL!
 - ARE PARTICIPANTS PROVIDING INSIGHTS TO OTHERS?!
 - WHEN OPPOSES SUP?
 - KNOW WHAT TO ASK!
 - KNOW HOW TO ENSURE THEY LISTEN!
 - WARM HOSPITALS AND INSURANCE DON'T SUPPORT THE MEDICINE OF CARE PLAN
- REIMBURSEMENT**
 - FUNDING
 - REIMBURSEMENT
- NOT LISTENING**
 - NEED FOR APPROVAL
 - SQUEEZED BY PHARMACEUTICAL CO. BY INSURANCE CO. BY HOSPITAL
 - BASED ON MT STAKE OF TREATMENT GOALS ALIGNED TO MY LIFE!
 - KIDS COLLEGE IMPACTS
- GAP IN EDUCATION**
 - STIGMA
 - EDUCATION FOR PATIENTS
- SDM**
 - LOOK AT INDICATIONS
 - LOOK AT THE BARRIERS
 - CULTURAL/LANGUAGE DIFFERENCES
 - INSURANCE
 - FEELING INTIMIDATED
 - CLARITY OF INFO
 - AUTHORITY OF VOICE
 - BEING SOMEONE ELSE
 - DR. PAYS BETTER ATTENTION DOESN'T DISREGARD ME
 - AS A WOMAN

Shared decision-making is a collaborative process where you and your doctor work together to choose the best treatment plan for your ITP. It gives you a chance to participate so that your values and preferences are incorporated in your plan.

Shared decision-making guides like this one are here to facilitate the process by suggesting questions to better understand treatment options, side effects, administration requirements, and other factors that will influence your care and daily life.

Talking about symptoms can be challenging, especially when they are not always visible or easily measured.

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A Roadmap for Every Step of the ITP Journey

Patient Empowerment and Shared-Decision Making

Prepare for appointments by writing down concerns and asking follow-up questions. This can make it easier to communicate what you are experiencing. Support from patient communities and advocacy organizations like PDSA can also help individuals feel more confident discussing symptoms and treatment goals.



Shared Decision-Making Tool: **The ITP Stoplight**

Unsure when to call your doctor or seek emergency help? Using a “Stoplight” tracker can help you identify when your symptoms of ITP need additional information.



Green Light means symptoms are manageable and daily activities are mostly unaffected.



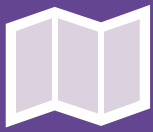
Yellow Light means symptoms are increasing or beginning to interfere with daily life, and you should contact your doctor or other medical professional.



Red Light means symptoms suggest a possible emergency and require immediate medical attention.

Use the form on the next page as a conversation starter with your medical provider to determine how to tackle your health conditions at home or in your community.





A Roadmap for Every Step of the ITP Journey

Patient Empowerment and Shared-Decision Making

“Stoplight” Conversation Starter

Instructions: Bring this tool to your medical professional to identify when the signs and symptoms of ITP may need additional medical attention.



	GREEN LIGHT	YELLOW LIGHT	RED LIGHT
	I will follow up with my physician at my next appointment on _____ DATE/TIME	I will take action <u>today</u> and call my doctor for an appointment at _____ PHONE NUMBER	I will take action <u>now</u> and call 9-1-1 or my doctor for emergency care at _____ PHONE NUMBER
Am I bleeding or bruised?	I'm noticing new bruises on my body, or my current bruises are taking a long time to heal. and/or I am noticing new petechia.	I'm having intense bleeding, such as: Nosebleeds that require me to change clothes, and/or Menstrual bleeding that soaks a sanitary pad or menstrual cup in less than an hour	I am bleeding uncontrollably and cannot stop the bleeding even when I apply pressure. and/or I have passed out or become unconscious and am having difficulty breathing. and/or I am experiencing critical bleeding and have gone into shock.
How is my fatigue?	I am feeling more tired than normal, even when I get rest.	I am fatigued or exhausted, and it is interfering with my work, school, or other daily activities.	I cannot stay awake, or I feel so exhausted that I cannot get out of bed.
Write down other symptoms that you'd like to discuss with your healthcare team in the gray boxes below.			

Based on emergency management guidelines for ITP, see: Chowdhury SR, Sirotich E, Guyatt GH, et al. Guideline on the emergency management of critical bleeding in patients with immune thrombocytopenia. *Blood Advances*.
<https://doi.org/10.1182/bloodadvances.2025018818>



A Roadmap for Every Step of the ITP Journey

Taking an Active Role in Your Treatment Plan

Taking an Active Role in Your Treatment Plan

Receiving an ITP diagnosis can bring a mix of difficult emotions. You may find a sense of relief at finally having an answer to what's happening with your body. At the same time, you may feel cautious about what comes next and what ITP means for your long-term health.

It's understandable to feel overwhelmed by a life-altering diagnosis. Taking an active role in your care, such as using this shared decision-making guide, can help you feel more prepared and confident in your decisions. It may also help you determine whether you need additional help.

Remember that ITP treatment planning isn't one-size-fits-all. Your priorities, symptoms, and goals will guide initial conversations and decisions with your care team. Then, how your body responds to treatments and further collaboration with your medical professionals may change the course you take.

The mission of this toolkit is to help you clarify what matters most so you can take an active role in your treatment plan. Shared decision-making can make it easier to ask questions, reflect on your goals, and work with your healthcare team to ensure treatment aligns with your preferences.

Rest Stop: Meet ITP Warrior Renata

Understanding your body

"Being diagnosed with immune thrombocytopenia at age 10 has been a drastic change in my life since I'm very active, from practicing a contact sport (taekwondo) and winning championships to just doing basic training.

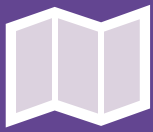
I never felt sick or had any other symptoms other than red spots in my body and face after a tournament. My parents took me to the doctor and they did blood work.

My platelet count was 3K. I was hospitalized for the following week with medication, and they went up to 30K. After 3 weeks, I got more bloodwork, and my platelets dropped again to 3K. I was hospitalized, but after that, my platelets are now at 10K.

My advice to other patients is to always be aware of every change your body may have, and always follow your doctor's directions for a speedy and healthy recovery. I hope everyone who is battling this disease gets better and healthy!"

Read Renata's full story at pdsa.org/patient-warrior-stories/2743-ity-warrior-renata.





A Roadmap for Every Step of the ITP Journey Taking an Active Role in Your Treatment Plan

Important Resources as You Get Started

Many people living with ITP will work closely with a hematologist, a doctor who specializes in treating conditions related to blood cells, bone marrow, and the lymphatic system. You may have worked with a hematologist to arrive at your ITP diagnosis, or you might start seeing one to help you decide on a treatment plan.

Hematologists can evaluate your test results, monitor platelet levels, and guide long-term treatment planning. As experts, hematologists can be a good resource when you have questions or concerns, especially about what treatments are available and how they may impact daily life.

Paying for Treatment

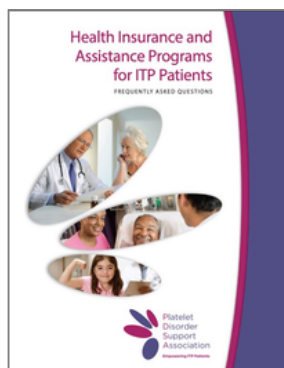
The cost of treatment can be a concern for many people living with ITP. Medications, monitoring, and ongoing care may create financial challenges, especially over time.

Talking openly with your healthcare team and medical insurer about financial concerns can help identify available resources. Some clinics offer financial counseling, limited expense reimbursement, patient navigation support, or case management services to help you understand coverage and out-of-pocket costs. Exploring available support options early can help reduce stress and make treatment more manageable.



Resources

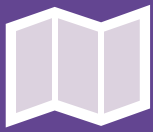
Navigating Insurance & Paying for Care



Health insurance providers may be unaware of complex and rare diseases, like ITP, making it harder to find care when you need it.

Use this booklet to understand how to navigate health insurance and to learn about other programs that may provide financial support during treatment.

Health Insurance and Assistance Programs for ITP Patients
pdsa.org/images/stories/pdf/InsuranceBooklet.pdf



A Roadmap for Every Step of the ITP Journey

Taking an Active Role in Your Treatment Plan

Understanding and Asking for What You Want

After diagnosis, one of the most important next steps in creating a treatment plan is stating what you want. Ask yourself what you want out of treatment, and how you want your daily life to look.

Is your top priority reducing bleeding risks? Are you worried about the effects of starting or stopping treatments? Is ITP currently keeping you from doing something you love or interfering with your ability to carry out daily activities, such as school, work, or travel? Take time to define what is most important to you.

Defining your treatment goals

People living with ITP often define a few different goals for their treatment plans:

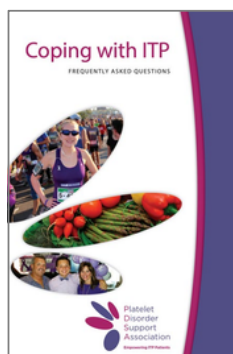
- Improving quality of life by addressing fatigue and other under-recognized symptoms
- Minimizing treatment side effects and symptoms
- Reaching a safe platelet count
- Reducing the number of infusions
- Preventing bleeding complications
- Having a longer time between blood tests
- Regaining the ability to do things they enjoy, like travel or work
- Addressing fears related to stopping treatment even when counts are stable

You can decide what matters and how much of your treatment planning focuses on improving symptoms, reducing uncertainty, or making ITP feel more manageable. Sharing your thoughts with your healthcare team helps them develop a more meaningful care plan that reflects your goals and medical needs.



Resources

Coping with ITP



Living with a chronic, rare disease can be difficult. Many people may need new strategies to cope with the physical and psychological impact of disease. Use this resource to identify new skills that can help you manage the disease.

Coping with ITP

pdsa.org/images/stories/pdf/Coping-with-ITP.pdf



How to Use Shared Decision-Making with Your Provider

Shared decision-making is a collaborative process where you and your healthcare team make choices together about your care. Instead of decisions being made *for* you, you are an active participant in defining treatment goals, concerns, and options.

For people with ITP, shared decision-making can help ensure that your treatment plans reflect both your lived experience and your healthcare team's medical expertise. This is an important combination because many ITP symptoms can be hard to evaluate with medical tests alone, such as fatigue and brain fog. Your perspective should shape your care so that these invisible signs and symptoms are addressed properly.

Engaging in shared decision-making is critical at every step of the patient journey. From the first office visit to managing ITP as a chronic disease, creating dialogue with your healthcare providers will enable you to advocate for yourself and your care goals.

The “Typical” ITP Patient Journey

While the experience of living with ITP varies from person to person, many in the ITP community have shared common milestones.

First Symptoms

Patients often experience symptoms such as easy bruising, frequent nosebleeds, or heavy menstrual bleeding. These symptoms may be intermittent or seem mild, leading patients to delay seeking care.

Initial Healthcare Encounters

Patients typically first see primary care providers, pediatricians, OB/GYNs, or emergency departments. Initial testing may be limited or inconclusive, and symptoms are often attributed to common conditions.

Misdiagnosis or Dismissal

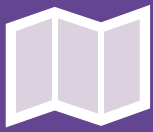
Because rare bleeding disorders are uncommon and variable, patients may be misdiagnosed or told their symptoms are normal, stress-related, or not serious, leading to frustration and delays in care.

Referral Delays

Referrals to hematologists or specialized centers are often delayed due to lack of awareness, a “wait and see” approach, insurance barriers, or limited access to specialists.

Specialist Evaluation

Evaluation by a hematologist is often the turning point, allowing for more comprehensive testing and consideration of rare diagnoses.



A Roadmap for Every Step of the ITP Journey

How to Use Shared-Decision Making with Your Provider

Eventual Diagnosis

Diagnosis provides validation but often comes after years of symptoms. Delayed diagnosis can result in avoidable complications and highlights the importance of timely referral and awareness.

How to Start the Conversation

For people with ITP, shared decision-making can help ensure that your treatment plans reflect both your lived experience and your healthcare team's medical expertise. This is an important combination because many ITP symptoms can be hard to evaluate with medical tests alone, such as fatigue and brain fog. Your perspective should shape your care so that these invisible signs and symptoms are addressed properly.

You can participate in shared decision-making by:

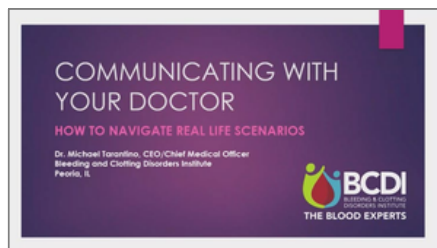
- Asking questions about treatment options and expected outcomes
- Sharing your treatment preferences and concerns
- Talking openly about how ITP and your current treatment affect your daily life
- Discussing short-term and long-term goals
- Asking about alternatives if a recommendation does not feel right for you

Participating in shared decision-making increases your own understanding of ITP. Depending on your symptoms, you might find it helpful to bring notes, use a symptom tracker, or involve a caregiver in your conversations. The more information you have, the easier it is for your healthcare team to tailor care to your needs and preferences.



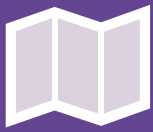
Shared Decision-Making Tool

Communicating with Your Doctor



Communicating with Your Doctor:
How to Navigate Real Life Scenarios
Dr. Michael Tarantino,
CEO/Chief Medical Officer,
Bleeding and Clotting Disorders Institute (BCDI)

Video Link: [Communicating with Your Doctor](#)



A Roadmap for Every Step of the ITP Journey

How to Use Shared-Decision Making with Your Provider

Accessing Treatments and Medications

Your ITP treatment plan will depend on several factors, including platelet counts, symptoms, bleeding risks, your insurance, your provider's capabilities, and personal preferences. Plans can also change over time depending on how you respond to medication and other interventions.

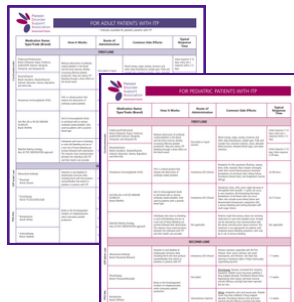
Your healthcare provider will work with you to determine appropriate treatment options. From there, you should have a conversation about how these options will meet your health and life goals, balancing elements such as symptom control, risk reduction, and daily goals.

There are several approaches to managing ITP, and treatment recommendations depend on individual circumstances. Each option comes with potential benefits and risks.



Resources Treatments

Find a comprehensive list of ITP treatment options, treatment tables and important considerations including complementary treatments and suggestions on improving your overall health at pdsa.org/treatments.



Adult ITP Treatment Grid

pdsa.org/images/AdultTreatmentGrid.pdf

Pediatric ITP Treatment Grid

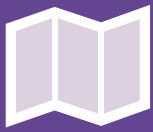
pdsa.org/images/PediatricTreatmentGrid.pdf

Documenting Treatment History and Care Planning

Keeping a record of your treatments can help you and your healthcare team track what works best over time. Treatment history to record can include:

- Medications you have taken
- Treatment schedules and dosage changes
- Side effects or reactions
- Changes in symptoms or platelet counts
- Questions or concerns that arise between visits

Having this information organized can make appointments more productive and ensure that treatment is focused on your goals.



A Roadmap for Every Step of the ITP Journey

How to Use Shared-Decision Making with Your Provider

Key Questions for Your Doctor

- | | |
|--|---|
| ☐ What treatment options are available to me? | ☐ How soon do I need to decide? |
| ☐ Which treatment do you recommend and why? | ☐ What happens if a treatment does not work? |
| ☐ What are the benefits and risks of each option? | ☐ What's the plan if something happens between treatments? |
| ☐ What side effects should I expect? | |
| ☐ How will treatment affect my daily life? | |

Barriers to Care

For many people living with a rare disease, provider bias is a reality when seeking access to care and treatment.² Just by being rare, someone living with ITP may face delayed diagnosis, a lack of knowledgeable providers, and limited access to treatment.

For those in underrepresented populations, finding help can be even harder. People living with rare diseases sometimes experience bias from their providers due to their age, race, ethnicity, gender, sexual orientation, or even where they live (such as rural or low-income neighborhoods).

What to do if you're experiencing these challenges?

First, know that you're not alone. Second, don't be afraid to bring your knowledge and lived experience to your doctor's office.

- Write down the signs and symptoms of your disease.
- Share your knowledge about your disease and ask the doctor specific questions.
- Don't be afraid to ask for a referral if you're not getting the care you need.
- Trust yourself to know what's right for you and your health.

Even though I had been bruising and experiencing fatigue for several months, my doctor told me that I was cured and didn't seem concerned about hearing my history or opening the door to any future treatment options. I am seeing a different doctor now and I do feel more prepared to mentally deal with ITP this time and I have more supporters in my life. - John P.

² Halley M, Halverson C, Tabor HK, Goldenberg AJ. Rare Disease, Advocacy and Justice: Intersecting Disparities in Research and Clinical Care. *Am J Bioeth.* 2023;23(7):17-26. <https://doi.org/10.1080/15265161.2023.2207500>



A Roadmap for Every Step of the ITP Journey Living with ITP



Resources

Inequities in the Rare Disease Community

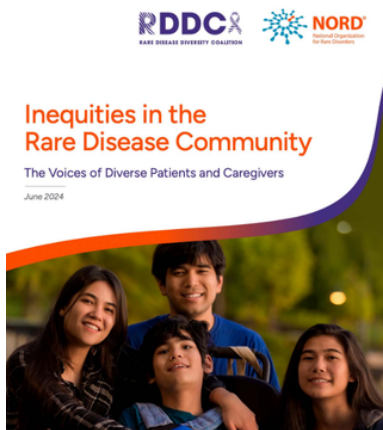


Image credit: Rare Disease Diversity Coalition

The Rare Disease Diversity Coalition (RDDC) is dedicated to addressing the extraordinary challenges faced by historically underrepresented rare disease patients as encompassed by social determinants of health (SDOH). The Coalition brings together rare disease experts, patients, health care professionals, diversity advocates, and industry leaders.

Working with the National Organization for Rare Disorders (NORD), RDDC released a comprehensive survey of over 2,800 rare disease patients and caregivers, illuminating barriers to care. Read the report, *Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers*, at rarediseasediversity.org/research-resources.

Living with ITP

Living with immune thrombocytopenia (ITP) means living with change and challenge throughout your life. Some people will only experience a short period of illness and recovery, while others live with ITP for many years. Your symptoms and treatment priorities may change over time, reflecting changes in your life.

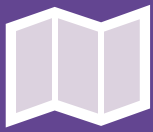
ITP can be acute or chronic. For many people, ITP will relapse even after periods of stability.

As you learn more about your condition and diagnosis, you will have a better understanding of how ITP may impact and shape your life. You may find yourself adjusting routines, changing habits or hobbies, and even thinking differently about your energy and time each day.

And our care teams change as we age. Consider creating a folder to track symptoms and concerns and bring it with you to ongoing appointments or meetings with new providers. Many ITP patients also bring broader PDSA resources to discuss with their healthcare team.

Using a shared decision-making framework will enable you to work with your healthcare team to develop a plan that reflects your medical needs and your preferences for daily life. Like ITP, these plans will change over time.

Living with a rare disease like ITP can be complex and frustrating. You may have to advocate for yourself more than others do, often explaining your condition to friends, family, and healthcare providers. Having the right tools and support network can make ITP more manageable.



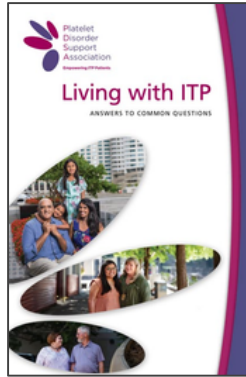
A Roadmap for Every Step of the ITP Journey

Living with ITP



Resources

Living with ITP



Once you've been diagnosed, you may have new questions about how to live with ITP from day-to-day. PDSA has resources for adults, children, and caregivers who are managing ITP.

Living with ITP

pdsa.org/images/stories/pdf/PDSA-Living-with-ITP.pdf

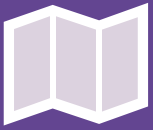
ITP Life Quality Assessment

Living well with ITP is not only about platelet counts. It is also about how you feel, what you can do, and the kind of life you want to maintain.

Thinking about quality of life can help you have more meaningful conversations with your care team and identify where additional support may be needed. Some people begin by asking broad questions such as:

- ☐ What does a good day look like for me? What about a week or a month?
- ☐ What activities or responsibilities matter most to me right now?
- ☐ Where does ITP affect my life the most?
- ☐ What feels manageable right now, and what does not?
- ☐ What am I avoiding because of symptoms, worry, or treatment demands?

These questions can help you look beyond lab results and think more clearly about how ITP affects other aspects of your life.



Patient Assessment Conversation Tool

Some people find it helpful to think about their care in more specific terms. Reflecting on practical questions can make it easier to prepare for appointments and to talk openly with your provider about what is and isn't working.

You may consider questions such as:

- ☐ What would make treatment feel less disruptive to my life?
- ☐ What side effects have the biggest impact on what I want to do?
- ☐ What would help me feel more stable and supported?
- ☐ What symptoms are hardest for me to explain to others?
- ☐ What tradeoffs am I willing to make? Which are too difficult?
- ☐ What would I like my provider to better understand about my experience?

Similar reflections can help you have a more productive conversation and support better shared decision-making over time.

Integrating Nurse Navigators

Some patients benefit from support beyond their physician alone. Nurse navigators and similar care professionals can help explain treatment plans, coordinate appointments, and answer questions between visits. In some cases, they also help you address barriers such as transportation and insurance problems.

The field of oncology has long been recognized for its leadership in nurse navigation, partnering with organizations such as the Academy of Oncology Nurse & Patient Navigators (AONN+) to develop tools and resources that support patient navigation and provide education and professional development for navigators. These established models and resources can be adapted to support patients with ITP. Training tools are available at aonnonline.org/navigation-tools.

For people living with a rare disease like ITP, this support can make the process more manageable. It can also reduce confusion during periods of change, whether that's switching medication or even care teams. Ask your clinic or health system if they offer nurse navigators.



A Roadmap for Every Step of the ITP Journey Living with ITP

Support Groups and Peer Resources

Living with ITP can feel isolating, especially when others do not understand the condition or the impact of its invisible symptoms. Support groups and peer communities might make your experience less lonely.

ITP support groups can help you:

- Learn how others manage symptoms and treatment
- Feel validated in experiences that may be hard to explain
- Gain confidence speaking with providers
- Find practical strategies for daily life



Resources

Finding Support

You don't have to manage the ITP journey alone. Find others who are living with ITP, including local or online support groups through PDSA.

Support Groups

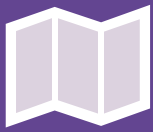
pdsa.org/support-groups

Advocating for Self-Care

The emotional impact of ITP is significant. Living with an unpredictable condition can affect stress, mood, sleep, relationships, and overall well-being.

If feelings of anxiety, frustration, sadness, or isolation begin affecting your daily life, it is important to discuss them with your care team. Support may come from counseling, peer communities, stress-management strategies, or other mental health resources.

Recognizing emotional health as part of your overall care can help you seek support earlier and feel more supported over time.



A Roadmap for Every Step of the ITP Journey Living with ITP



Resources

Support for Mental Health and Wellness

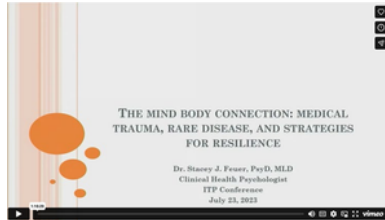
The Mind Body Connection: Medical Trauma, Rare Disease and Strategies for Resilience

In 2023, PDSA hosted its annual ITP Conference where Stacey J. Feuer, PsyD., MLD provided a keynote address on medical trauma and led an interactive discussion on her experience as a person living with rare disease and as a licensed clinical health psychologist.

Medical traumatic stress might derive from the mental and physical health responses to pain, illness, medical procedures, invasive or frightening treatment. Being aware of the symptoms and treating acute stress disorder early significantly decreases the chance of acute stress disorder becoming PTSD.

As she described, “What is important is to have access to trauma informed care from medical professionals who are knowledgeable about medical traumatic stress and who will communicate collaboratively with the patient. It is important for doctors to understand how traumatic medical events or stress can impact health outcomes.”

Learn more at the link below.



The Mind Body Connection:
Medical Trauma, Rare Disease,
and Strategies for Resilience
Dr. Stacey J. Feuer, PsyD, MLD
Clinical Health Psychologist

Video Link: [The Mind Body Connection: Medical Trauma, Rare Disease, and Strategies for Resilience](#)

Other Mental Health Resources

National Alliance for Mental Illness (NAMI)
nami.org

Mental Health America (MHA)
mhanational.org

Mental Health and Substance Use (Substance Abuse and Mental Health Services Administration – SAMHSA)
samhsa.gov/find-support

Mental Health (Centers for Disease Control and Prevention – CDC)
cdc.gov/mental-health/caring



A Roadmap for Every Step of the ITP Journey Advocating for Yourself and Your Community

Advocating for Yourself and Your Community

Living with ITP often requires self-advocacy. This may include asking questions, requesting referrals, explaining symptoms that are not visible in lab results, or speaking up when treatment does not feel aligned with your goals.

Supportive care considers more than platelet counts alone. It also includes fatigue, cognitive symptoms, emotional health, daily responsibilities, and access to care.

Understanding Your Rights



YOUR ITP PATIENT BILL OF RIGHTS
Every person with ITP deserves empowered, informed, and respectful care.
This Patient Bill of Rights defines the principles and expectations for equitable, compassionate, and personalized treatment. It fosters trust, advocates for well-being, and strengthens partnerships between patients and care teams.

AS AN ITP PATIENT, YOU HAVE THE RIGHT TO:



Scan the QR code to learn more or visit pdsa.org

1 Understand Your Diagnosis Receive a clear, understandable diagnosis , which includes all related diagnostic testing, and have the option to seek a second opinion from an ITP specialist.	2 Explore Treatment Options Be informed of all available treatment options , and not have your treatment plan dictated by insurance or physician preferences.	3 Share Decision Making Participate in shared decision-making with your doctor to create a treatment plan aligned with your lifestyle and preferences.	4 Access Medication and Financial Support Obtain necessary medications and treatments as recommended by your doctor, and find financial assistance if needed to cover care and treatment.	5 Stay Informed Access accurate, up-to-date information such as ITP treatment guidelines from trusted sources such as academic institutions, healthcare professionals, and the Platelet Disorder Support Association.
6 Prioritize Quality of Life Ensure your healthcare provider addresses your quality of life , considering both physical and mental health.	7 Involve Your Support Network Involve your support network – caregivers, family, and friends – in conversations with healthcare providers.	8 Participate in Clinical Trials (When Eligible) Learn about clinical trials and participate in those for which you are eligible.	9 Connect with the ITP Community Connect with the ITP community to share experiences , gain insights, and alleviate feelings of isolation.	10 Be Treated with Dignity and Respect Be treated with dignity and respect regardless of age, gender, ethnicity, or health status, fostering a supportive and understanding medical environment.

pdsa.org/treatments/bill-of-rights

Advocacy can also mean clearly sharing your experiences, concerns, and priorities. For some, advocating with health systems, state or federal lawmakers, or in community settings is meaningful because it increases public awareness and allows people living with ITP to act.



Resources Advocating for Better ITP Care

PDSA offers multiple ways to learn how to advocate for ITP, whether at your doctor's office, in your community, or with lawmakers. For more information, visit: pdsa.org/advocacy



A Roadmap for Every Step of the ITP Journey Acknowledgements

Acknowledgements

We gratefully acknowledge the members of the ITP Patient and Caregiver Advisory Board, convened in July 2025, for their invaluable contributions to the development of this shared decision-making toolkit.

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Illustrations from the ITP Patient and Caregiver Advisory Board were created by ImageThink during the July 2025 ITP conference in Philadelphia, PA.

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A Roadmap for Every Step of the ITP Journey For Medical Professionals: ITP and Your Patients

For Medical Professionals: ITP and Your Patients

A diagnosis of Immune Thrombocytopenia (ITP) can be overwhelming for patients, who often leave initial appointments with limited information, unanswered questions, and uncertainty about next steps. Providing patients with trusted resources at the time of diagnosis is critical to supporting their understanding, engagement, and confidence in managing their condition.

This toolkit provides ITP-related information to support your patients in shared decision-making.

We encourage you to read through this information and share the final tear-off page with newly diagnosed ITP patients. It will refer them to the Platelet Disorder Support Association (PDSA), a leading patient advocacy organization dedicated to enhancing the lives of patients with ITP and other platelet disorders through education, advocacy, research and support.

PDSA also provides access to patient support networks, peer communities, and ongoing education and support beyond the clinical setting. Connecting patients with PDSA early in their journey can help bridge information and support gaps, ensuring they feel informed, supported, and empowered as they navigate their diagnosis.

What is Immune Thrombocytopenia?

Immune thrombocytopenia is a complex autoimmune blood disorder where the immune system may mistakenly target platelets, affecting both the destruction of platelets and can interfere with the body's ability to produce new platelets.

ITP is often triggered by other factors that cause the immune system to react, such as viral and bacterial infections, reactions to medications or some vaccines, or other immune conditions.

Symptoms such as unexplained or easy bruising, bleeding, and petechiae. In severe cases, patients may have internal or intracranial bleeding. Roughly half of adults with ITP also report fatigue and an impaired quality of mental and emotional health, physical health, and social functioning. ITP impacts between 4 to 5 out of every 100,000 children and 3 to 8 out of every 100,000 adults. Unfortunately, its causes and symptoms can vary significantly, making it difficult to diagnose.

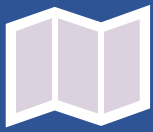
Diagnostic Tools

ITP is a diagnosis of exclusion. In addition to the patient's medical history, you may also want to consider a series of other tests for adults or children experiencing symptoms of ITP:

- Complete blood count (CBC)
- Blood smear
- Bone marrow exam
- Coagulation tests
- Quantitative IG level testing
- Direct anti-globulin test
- H pylori testing
- Testing for other acute and persistent infections

For adult patients, this additional diagnostic tool is recommended:

- Immature Platelet Fraction (IPF) / Reticulated Platelets (RP%)



A Roadmap for Every Step of the ITP Journey For Medical Professionals: ITP and Your Patients

Consensus-Based Practice Guidelines



Cuker A, Terrell DR, Sowdagar H, et al. American Society of Hematology 2026 guidelines for immune thrombocytopenia (ITP): initial and second-line therapy in adults with primary ITP. *Blood Advances*. 2026. <https://doi.org/10.1182/bloodadvances.2026021269>



Chowdhury SR, Sirotich E, Guyatt GH, et al. Guideline on the emergency management of critical bleeding in patients with immune thrombocytopenia. *Blood Advances*. 2026. <https://doi.org/10.1182/bloodadvances.2025018818>



Provan D, Arnold DM, Bussel JB, et al. Updated international consensus report on the investigation and management of primary immune thrombocytopenia. *Blood Advances*. 2019. <https://doi.org/10.1182/bloodadvances.2019000812>

Clinical Tools and Resources

From the Platelet Disorder Support Association (PDSA)



Understanding Your Diagnosis

pdsa.org/understanding-your-diagnosis

Patient-centered overview of ITP, including expert-explained videos and frequently asked questions.



Health Care Provider Resources

pdsa.org/health-care-provider-resources/hcp-resources

Clinical and practice resources, including:

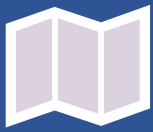
- Health Care Provider Toolkit
- Guidelines & Clinical Management
- Special Management Considerations
- Patient Education Resources
- PDSA Publications & Presentations
- Clinical Trials
- PDSA Research Grant Programs
- ITP Natural History Study Registry
- CME - Accredited Webinars



PDSA's Annual ITP Patient Conference

pdsa.org/conferences

PDSA welcomes patients, caregivers, and healthcare professionals to its premier event for education, support, and connection.



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Risk Factors for Mortality

According to a 2025 study, there are significant racial and socio-economic disparities among patients in terms of hospitalizations and mortality. Minority populations, particularly Asian or Pacific Islander, African American, and Native American patients, experienced higher mortality rates and increased risk of complications such as sepsis and acute kidney injury compared to White patients.

Researchers noted that the statistically significant differences ($p < 0.001$) may reflect underlying disparities in health status, access to timely care, or disease severity at presentation.

ITP-related mortality risks broadly increase with severe hemorrhages (especially intracranial), high-risk infections, and complications related to treatment. Age, chronic or refractory disease, and comorbidities are also risk factors for mortality in ITP patients.

See: Mathew T, Varghese TM, Varghese GM. Unequal Burden: Racial Differences in Mortality, Complications, and Resource Utilization in Immune Thrombocytopenia Hospitalizations. *Cureus*. 2025;17(7). <https://doi.org/10.7759/cureus.87242>

Medications and Treatments

- Antibiotics
- Anti-Rho(D)
- B-Cell Depletion Therapy
- Chemotherapy
- Corticosteroids
- Immunosuppressants
- Immune Modulation
- Intravenous Immunoglobulin (IVIG)
- Modified Testosterone
- Platelet Destruction Inhibition
- Platelet Growth Factors
- Splenectomy



Treatments

pdsa.org/treatments/conventional

Find a full list of conventional and complementary treatments for ITP, including adult and pediatric treatment tables, from PDSA.

Shared Decision-Making Toolkit Flyer

If you are a medical professional, please print and share the flyer below with your patients to help them understand ITP and shared decision-making.



Living with ITP? You have a voice in your care.

Shared Decision-Making with ITP

Immune thrombocytopenia (ITP) is an **autoimmune disorder** characterized by immune-mediated platelet destruction and impaired platelet production, leading to an **increased risk of bleeding**. Beyond bleeding, ITP is associated with **substantial quality-of-life impairment**, including fatigue, cognitive difficulties, anxiety, and depression, which may occur independently of platelet count. Unpredictable disease course, ongoing monitoring, and treatment-related adverse effects can further limit participation in work, school, physical activity, and social roles, with downstream effects on caregivers and families. **Recognition of these patient-reported burdens is essential to shared decision-making and individualized treatment selection.**

The **Platelet Disorder Support Association (PDSA)** and our partner organizations have created a **shared decision-making toolkit** to help you understand ITP and related treatment. With the toolkit, you can:

- Review and understand symptoms.
- Discover what information to share with your care team and what questions to ask them.
- Learn how to set goals for your care based on your wishes and preferences.
- Find resources designed to help people living with ITP.



Toolkit for Patients and Medical Professionals

A Roadmap for Every Step of the ITP Journey is a free resource created for people living with ITP and medical professionals to help improve your ability to direct your ITP care.

If your doctor is unfamiliar with ITP, you can also share the toolkit with them at your next appointment.

Download your free copy of the toolkit by scanning the QR code below:



For more information on ITP, visit: pdsa.org



Platelet
Disorder
Support
Association

Empowering ITP Patients

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