

■ What is ITP?

Immune thrombocytopenia (THROM-bo-si-to-PE-ne-ah) or ITP is a rare autoimmune condition that can be as challenging to pronounce as it is to live with. Characterized by low blood platelet counts, you may hear ITP called by its original name of idiopathic thrombocytopenic purpura. Historically, “idiopathic” was used because the cause of the condition was unknown. Today we know ITP is a disease of platelet destruction in which the body’s immune system destroys healthy platelets and research advances have also shown that many people with ITP also have a platelet production problem. Increased platelet destruction and impaired platelet production lead to easy or excessive bruising and bleeding, in addition to initiating a daily roller coaster of emotions and ongoing medical management.

Platelets are relatively small, disc-shaped cells circulating within the blood that bind together when recognizing damaged blood vessels. When you get a cut, platelets bind to the site to cause a blood clot—and stop the bleeding. A normal platelet count is between 150,000 and 450,000 per microliter of blood. If someone has a platelet count lower than 100,000 per microliter of blood with no other reason for low platelets, they are considered to have ITP. Learn more about the purpose of platelets at PDSA.org.

■ The Phases of ITP

Newly Diagnosed ITP: within 3 months from diagnosis

Persistent ITP: 3 to 12 months from diagnosis

Chronic ITP: lasting for more than 12 months

■ What Causes ITP?

The specific cause behind why ITP develops is usually unknown and can differ from person to person. ITP has been shown to develop:

- After a viral or bacterial infection
- After certain immunizations
- After exposure to a toxin
- In association with another illness, such as lupus or HIV (human immunodeficiency virus)

Learn more about the science behind the causes of ITP at PDSA.org.

■ What are the Symptoms of ITP?

The symptoms of ITP can vary greatly from person to person, and some with ITP may show no signs of having the condition. In general, the lower your platelet count, the more symptoms you may have including:

- Easy or excessive bruising (purpura)
- Petechiae (pe-TEEK-ee-ay), tiny red dots on the skin caused by broken blood vessels or leaks in a capillary wall
- Bleeding from the gums or nose
- Blood in urine or stools
- Unusually heavy menstrual flow
- Feeling tired or fatigued

■ How is ITP Diagnosed?

ITP is a diagnosis of exclusion. Because there is no definitive test to diagnose ITP, practitioners rule out other causes of low platelets, such as an underlying illness or medications. If no other cause is found, the diagnosis is often ITP.

In addition to recording medical history, a practitioner will perform a physical exam and run one or more of the following tests:

- Complete blood count (CBC)
- Blood smear
- Bone marrow exam: The American Society of Hematology doesn’t recommend this test for children with ITP.

Learn more about the tests used to diagnose ITP and important information to share with your doctor for the correct diagnosis at PDSA.org.

■ How is ITP Treated?

Once ITP is diagnosed, the primary goal is to develop the best treatment plan with a hematologist to control symptoms and improve quality of life. If mild bruising and petechiae are the only symptoms experienced, a doctor may simply wait on beginning any treatment and watch and actively monitor the condition over a period of time. If symptoms are more severe, prompt treatment may be recommended to raise platelet counts to lower the chance of uncontrolled bleeding. While there is no cure for ITP, many patients find their platelet count improves following treatment.

Learn more about conventional and complementary treatments in managing ITP at PDSA.org.

■ Our Mission

The Platelet Disorder Support Association is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support.

■ About PDSA

Patient-founded in 1998 to educate and empower those impacted by ITP and other rare platelet and bleeding disorders, PDSA is now a powerful force serving and unifying the global 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.

PDSA receives no federal funding. It never has. Charitable gifts from our individual and corporate donors, membership contributions, and inspiring awareness and philanthropic events coordinated by committed volunteers energize, uphold and preserve our mission.



For an extensive patient-focused library of current disease, treatment and research information, and patient-centric programs and services, visit www.PDSA.org.

CONNECT WITH US!

 **15,000+**
Followers of the PDSA Facebook page

20,000+
PDSA Facebook group members

Visit our Facebook page and join our closed group!

 **2,700+**
Instagram Followers

 **1,700+**
X Followers

 **237,000+**
YouTube Video Views

1,200+
PDSA YouTube Subscribers



Platelet Disorder Support Association

Empowering ITP Patients

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For online giving, please visit www.PDSA.org.

All donations are fully tax deductible to the extent of the law. PDSA is a 501(c)3 charitable organization and is eligible for corporate matching grants. EIN: 22-3611011

ITP

Immune Thrombocytopenia

Tough to pronounce.
More challenging to live with.



Platelet Disorder Support Association
Empowering ITP Patients

Education. Advocacy. Research. Support.

PROGRAMS AND SERVICES

3 Websites

PDSA.org
ITPwalk.org
globalITP.org



16

Newsletters
Per Year



12

Educational
Booklets
translated into
multiple languages



PDSA College
Scholarship

60+

Local Support
Groups



1,800+

Patient Questions
Answered Each Year



CONNECT

■ ITP Patient Connect Local Support Groups

60+ local groups in the US and Canada and 2 groups via teleconference.

■ Annual ITP Conference

Priceless forum and lifeline for patients and esteemed training symposium and lesson on the patient journey for health care and industry professionals.

■ ITP HelplineSM

Connects patients and caregivers to life-altering information, resources and referrals.

■ Awareness Month

Founded in 2010 by PDSA, National ITP Awareness MonthSM has become a global movement. Each September, the ITP community celebrates around the world with activities throughout the month, including the last Friday of September as Sport Purple for Platelets DaySM, and the last week of September as Global ITP Awareness WeekSM.

■ Pump It Up For Platelets! National Walk/Run and DIY Fundraising Events

Unite patients and communities, raise public awareness, provide essential funding to support life-changing programs and groundbreaking research, and foster hope in the quest to heal. Visit www.ITPwalk.org and www.PDSA.org.

■ Social Networks

PDSA's Facebook page and closed group, Instagram page, X (*Twitter*) channel and YouTube channel are treasured communities of engaged followers and influencers who look to PDSA to connect online and widen the circle of awareness.



National ITP Awareness Month
Global ITP Awareness Week



EVENTS

- ✓ Annual ITP Conference
- ✓ Sport Purple for Platelets DaySM
- ✓ National Walk/Run

COLLABORATE

■ The Barbara and Peter T. Pruitt Jr. Research Award

Awards two \$20,000 annually to investigators conducting innovative ITP patient-centered research.

■ The James B. Bussel, MD ITP Young Investigator Award

Supports promising academic ITP research projects.

■ ITP Patient Assessment Questionnaire (ITP-PAQ)

Research instrument designed to measure Quality of Life issues of ITP patients.

■ ITP Natural History Study Patient-Consented Registry

International patient-consented registry of individuals with ITP designed to gather data on the natural progression of ITP, diagnosis and treatment, management of care, quality of life, and clinician reporting.

■ International ITP Alliance

Co-founded by PDSA, the intercontinental partnership of 35 ITP patient support groups representing 30 countries is committed to education, awareness and establishing a global voice for immune thrombocytopenia patients.

Research
Grants

\$50,000

Awarded Annually

\$300,000+

Total Granted Since 2017

16

Advocacy
Partnerships



■ Annual International ITP Alliance Symposium

Connects International ITP Alliance groups with key advocates and opinion leaders, provides insight into global health care plans and promotes improved patient-centric policies.

■ GlobalITP.org Website

Serves 3,655 monthly visitors from 157 countries as the international gateway for disease information, patient support, clinical trials and innovative global studies and research data.

■ Translated Educational Publications

Educates the global ITP community with patient-friendly materials in multiple languages.

■ Advocacy Partnerships

Advocacy partnerships are crucial in driving public policy, developing new treatment options and funding research to find a cure. PDSA ensures patient-centric outcomes are the driving force behind all healthcare decisions and quality measurements and collaborates with patient advocacy groups, researchers and government agencies around the globe including:

- ASH – American Society of Hematology
- FDA Alliance
- Genetic Alliance
- ICON – Pediatric ITP Consortium of North America
- NORD – National Organization for Rare Disorders
- THSNA – Thrombosis & Hemostasis Society of North America

