

■ 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 has never received any federal funding. 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 online giving, please visit PDSA.org.

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

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22,000+
PDSA closed Facebook group members

 **4,000+**
Instagram Followers

 **1,700+**
X Followers

 **250,000+**
YouTube Video Views
1,380+
PDSA YouTube Subscribers

 **650+**
LinkedIn Connections

 **600+**
Podcast Streams
*Bruised but not Broken:
Living with ITP*

 Platelet Disorder Support Association
Empowering ITP Patients

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ITP
Immune Thrombocytopenia



 Platelet Disorder Support Association
Empowering ITP Patients

Education. Advocacy. Research. Support.

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



PROGRAMS AND SERVICES

2 Websites

PDSA.org
globalITP.org



 **Monthly**
E-news
Quarterly
28-page newsletter



12

Educational
Booklets
translated into
multiple languages



PDSA College
Scholarship

65+

Local Support
Groups



1,000+

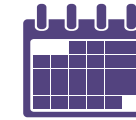
Patient Questions
Answered Each Year



SEPTEMBER
National ITP Awareness Month
Global ITP Awareness Week

EVENTS

- ✓ Annual ITP Conference
- ✓ Sport Purple for Platelets DaySM
- ✓ Pump It Up for Platelets! Walk/Run and Fundraising Events
- ✓ Annual International ITP Alliance Symposium



Research Grants



\$50,000

Awarded Annually

\$410,000+

Total Granted Since 2017

35

International
ITP Alliance
Partners



CONNECT

■ **ITP Patient Connect Local Support Groups**
65+ local groups in the US and Canada and 2 groups via teleconference.

■ **ITP Teen Connect**
A safe space for teens to gather, learn, and grow, while meeting the unique needs of teens with ITP through quarterly virtual programming and events.

■ **Annual ITP Conference**
For more than 25 years, the Annual ITP Conference has provided updates on the latest information about ITP and connected the global ITP community of patients, caregivers, industry and healthcare professionals, and ITP experts.

■ **ITP HelplineSM**
Connects patients and caregivers to accurate and vital 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 Global ITP Awareness Week the final full week of the month, and Sport Purple for Platelets Day on the last Friday of September.

■ **Pump It Up For Platelets! National Walk/Run and Fundraising Program**
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 PDSA.org.

■ **Social Networks**
PDSA's Facebook page and closed group, Instagram, X, LinkedIn, and Youtube channel connect engaged and active communities of ITP patients, caregivers, and influencers to provide support and promote ITP awareness.

COLLABORATE

■ **The Barbara and Peter T. Pruitt Jr. Research Award**
Awards two \$20,000 grants annually to investigators conducting innovative ITP patient-centered research.

■ **The James B. Bussel, MD ITP Young Investigator Award**
Awards one \$10,000 scholarship annually to support 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.

■ **GlobalITP.org Website**
Serves thousands of visitors from more than 150 countries as the international gateway for disease information, patient support, clinical trials and innovative global studies and research data.

■ **Advocacy Partnerships**
Advocacy partnerships are crucial in driving public policy, developing new treatment options and funding research to find a cure. PDSA collaborates with patient advocacy groups, researchers and government agencies around the globe including:

- ASH - American Society of Hematology
- BMC - Best Medicines Coalition
- CBS - Canadian Blood Services
- CORD - Canadian Organization for Rare Disorders
- FDA Alliance
- ICON - Pediatric ITP Consortium of North America
- NCAPG - National Coalition of Autoimmune Patient Groups
- NORD - National Organization for Rare Disorders
- NRBDO - Network of Rare Blood Disorders Organization
- THSNA - Thrombosis & Hemostasis Societies of North America

EMPOWER

■ **PDSA.org Website**
Trusted online resource for disease, treatment and research information with more than 36,700 unique visits per month from over 200 countries.

■ **Patient and Public Education**
12 patient-friendly educational booklets, translated into multiple languages, are available for free online and select booklets in hard copy by request.

■ **Publications**
Monthly free e-news and quarterly member publication, *The Platelet News*, report breaking news, research findings, treatment updates, patients stories, and upcoming events.

■ **ITP Poke-R ClubSM**
Award-winning clinical support program developed to empower kids with ITP.

■ **PDSA College Scholarship**
Over \$40,000 in financial assistance has been awarded to graduating high school seniors, college students, and adults living with ITP or another low platelet disorder since the program was established in 2008.