

ITP

immune thrombocytopenia

**You treat
the disease.**



Platelet
Disorder
Support
Association

Empowering ITP Patients

**We treat
its isolation
and fear.**



Empowering You and Your Patients

The Platelet Disorder Support Association (PDSA) was created to improve the lives of everyone touched by Immune Thrombocytopenia (ITP) and other platelet disorders. That includes medical professionals like you who seek answers to your patients' platelet deficiencies through clinical pathology and the latest scientific research.

Because of the underlying pathophysiology and natural history of the disease, most patients have longstanding thrombocytopenia, making the management of ITP unpredictable despite different avenues of therapeutic action. In addition to concerns about their platelet counts, ITP patients live with an ever-present fear of relapse and recurrent bleeding.

You, no doubt, have seen the fear and frustration ITP leaves in its wake. You know solutions are seldom simple and often require thoughtful trial and error and customization. You've also seen the anxiety ITP patients develop while they await treatment results.

Raising ITP Patient Expectations

PDSA exists to offer support and life-changing information to those who suffer from ITP and other platelet disorders. Our mission is not to recommend treatments, but to educate patients, connect them with the work of ITP experts and to share the journeys of others suffering from ITP so that they don't feel so isolated.

PDSA provides patients with the 24/7 support they need to cope with the fear and anxiety of their condition. We advocate for ITP patients' rights here in the U.S. and across the globe. And for you, the physician, we offer a dependable source for the latest ITP protocols, research and therapies being developed worldwide, along with information you can share with your patients to help educate and support them.



Persons with ITP seek answers

Most likely, you've received panic calls at all times of the day and night from ITP patients, frightened parents of ITP children or concerned caregivers who simply do not know what to do next. Some of the treatment options you and your ITP patients cycle through work only temporarily while some remain effective for long periods of time. Still, none reliably or predictably cure ITP.

The possibility of serious internal brain bleeding caused by something as small as a cough or an accidental bump is ever top of mind for your ITP patients. Equally present are the anxieties over the dangers of surgery or the complications of pregnancy.

As a medical professional you are tasked with answering many of these real-life concerns. With over 50,000 people in the U.S. currently living with ITP, you will certainly face ITP questions sometime during your medical career. With the advances in medicine occurring at rapid speed these days, keeping up with ordinary disease therapies is difficult enough without adding the fast-paced improvements being made in a rare disease like ITP.

PDSA tackles some of its toughest questions

The good news is PDSA connects you and your patients with the information and knowledge you need to beat ITP, both clinically and psychologically. We empower ITP patients with the latest news, treatment information and research to help them understand that there is more to coping with the disease than just watching their platelet counts.

We provide medical professionals with the latest information about the disease through our online resources, disease guides, newsletters and by funding research that may lead to future breakthroughs for adults and children living with ITP.

An Invitation to Infuse Your ITP Patients with Hope

Patients with ITP are experts at living with ITP. They tire of the limitations ITP places on their lives. They want better diagnostic tests and more safe and effective treatments to improve the quality of their lives.

You can help your ITP patients by connecting with PDSA, by taking advantage of our HCP resources, forums and conferences, signing up for the monthly PDSA e-News, utilizing our many online videos, and by becoming a Professional PDSA Member.

You can also help ITP patients achieve their goals by introducing them to PDSA. By sharing our patient-friendly information and resources and by helping them connect with their peers, you'll help ITP patients overcome their sense of isolation and turn their fears into the indestructible confidence that comes from knowing they are not alone.

Join us in creating brighter futures for people with Immune Thrombocytopenia. Visit www.PDSA.org and become part of the support community that empowers ITP patients.



89%

89% of ITP patients
complain of fatigue

47%

47% reported needing help
with anxiety concerning their
platelet counts

53%

53% found it hard to focus
because of their anxiety

Clinical Symptoms vs. Symptomatic Fears

Petechiae, purpura, gastrointestinal, urinary track bleeding or intercranial hemorrhage, the risk of thrombosis or thromboembolisms – you know the dangers associated with ITP. But what about the mental anguish ITP patients face?

According to Mental Health and Treatment in Patients with Immune Thrombocytopenia (ITP); Data from the Platelet Disorder Support Association (PDSA) Patient Registry, both symptoms of ITP and side effects from treatments impact patient QoL, commonly anxiety and fatigue. Registry respondents (n=385) reported use of one or more of 16 different treatments to manage their ITP.

Patients with ITP feel the impact of disease beyond the physical manifestations like bleeding and bruising, extending to the emotional impact of ITP. In part this is due to the uncertainty of symptoms, treatment efficacy and fear of the unknown.

PDSA AT A GLANCE

PDSA has served the ITP community for over twenty years, leading the way in ITP research by partnering with the scientific community as well as industry and government to develop new treatments and inject the patient perspective into the regulatory process.

14 MEDICAL ADVISORS

PDSA'S Medical Advisory Board includes renowned clinicians and researchers, all of whom are ITP specialists currently working on finding new ways to treat and someday cure ITP.

Donald Arnold, MD

McMaster University
Hamilton, ON (Canada)

James Bussel, MD

Cornell University
New York, NY

Douglas Cines, MD

University of Pennsylvania
Philadelphia, PA

Nichola Cooper, MD

Hammersmith Hospital
London, UK

Terry Gernsheimer, MD

University of Washington
Seattle, WA

Andra James, MD

Duke University
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Craig Kessler, MD

Georgetown University
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David Kuter, MD

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Michele Lambert, MD

Children's Hospital
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Howard Liebman, MD

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Diane Nugent, MD

University of California,
Irvine School of Medicine
Orange, CA

Drew Provan, MD

Barts & The London
Queen Mary's
London, UK

John Semple, PhD

St. Michael's Hospital
Toronto, Canada;
Lund, Sweden

Michael Tarantino, MD

The Bleeding and Clotting
Disorders Institute
Peoria, IL



PDSA.org; ITPwalk.org; globalITP.org

Many medical professionals tell us our web content is indispensable;

Our more than 1,000 pages of up-to-date research, guidelines, treatment management articles and videos, and patient stories are accessed through 80,000 visits a month.

SOCIAL MEDIA FOOTPRINT

ITP needs a place to share its challenges as well as its victories, you and your patients can find us on Facebook, Instagram, Twitter and LinkedIn; we provide educational video and vital discussion for tens of thousands involved with ITP.



RESEARCH *at* PDSA

The key to unlocking a cure

www.PDSA.org

Each year, PDSA provides 2-3 \$20,000 research grants to fund patient-centric ITP research to help find answers and possibly a cure based on ITP patient's chief complaints and burden of disease. The ITP Natural History Study Registry is administered by PDSA and a committee of leading hematologists, through a cooperative agreement with the National Organization for Rare Disorders (NORD) and the U.S. Food and Drug Administration (FDA). The registry collects diagnosis and treatment information through an international patient-consented database and provides published data including Quality of Life and demographics of patients with immune thrombocytopenia.

LOCAL SUPPORT GROUPS



Our 59 local support groups are spread across the U.S. as well as Canada and New Zealand; you can recommend one near you to ITP patients and their families with the confidence of knowing they'll be getting the latest, most accurate information they need to cope with the disease.

NATIONAL WALK/RUN FUNDRAISERS

Funding sustains PDSA; in recent years, our National fundraisers have allowed us to fund more research and raise ITP awareness worldwide.

HELPING ITP KIDS COPE

ITP kids hate needles, yet they need more blood drawn than most people; our ITP POKE-R CLUB™ helps your youngest ITP patients overcome their needle phobias and fears.

PDSA GOES TO WASHINGTON

Our medical advisors, board of directors, staff, and key volunteers act as advocates in Washington, DC, advocating for NIH, CDC and ITP research, ITP drug trials and ITP awareness programs in communities like yours across the country.

ANNUAL ITP PATIENT CONFERENCE, ALLIANCE FORUMS & OVER 200 AWARENESS EVENTS NATIONWIDE

Our annual ITP Patient Conference draws over 275 attendees; ITP patients, caregivers, doctors, nurses, researchers, and industry representatives come to our lectures and presentations; they exchange ideas and learn of possible new management solutions.

PDSA organizes the annual American Society of Hematology (ASH) Friday Morning ITP Breakfast, where global investigators present the latest cutting-edge ITP research.

PDSA oversees the International ITP Alliance, with 32 ITP patient associations representing 27 countries and the website globalITP.org.

PDSA organized the first Externally-led Patient-Focused Drug Development Meeting (EL-PFDD) on Immune Thrombocytopenia with the U.S. Food and Drug Administration (FDA).

Other Advocacy Partnerships include:

AARDA – American Autoimmune Related Diseases Association

A-Plus – American Plasma Users Coalition

ASH – American Society of Hematology

CPAG – Coalition of Patient Advocacy Groups

FDA Alliance

Genetic Alliance

IAPO – International Alliance of Patients' Organizations

ICON – Pediatric ITP Consortium of North America

NORD – National Organization for Rare Disorders

PPTA – Plasma Protein Therapeutics Association

THSNA – Thrombosis & Hemostasis Societies of North America

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.

**EDUCATION. ADVOCACY.
RESEARCH. SUPPORT.**



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