



2015 Annual Report

Education
Advocacy
Research
Support



 **PDSA**
PLATELET DISORDER
SUPPORT ASSOCIATION

for People with ITP

Dear Friends of PDSA,

From the Executive Director

I am proud to present the Platelet Disorder Support Association's 6th Annual Report, which differs slightly from those in prior years. In addition to recognizing all those who support PDSA and make possible the important work we do, this year's annual report shares even more of our favorite photos of ITP patients and their loved ones, and informational graphics that illustrate how PDSA is making the connection to ITP.



Last year brought many changes to our organization. The biggest change in 2015 was the physical move of our office from Rockville, Maryland, where PDSA was headquartered for 12 years, to our new home in Cleveland, Ohio. Along with the move came the hiring of three new staff members. These exciting changes allowed the organization to reduce costs and have the expert personnel in place to expand our programming and resources to better support ITP patients and their caregivers.

We are immensely proud of the work that we do, from our educational and support services through the PDSA Web site, discussion group and social media outlets, to our numerous publications and local support groups and annual conference, to our patient referral line. But none of the life-changing, and even life-saving, information PDSA provides to tens of thousands of patients each year would be possible without you.

PDSA receives no federal funding. It never has. That is why the support of our individual and corporate donors, along with the efforts of our fundraisers and volunteers is crucial in helping PDSA to fulfill its mission. Whether you supported PDSA with a charitable gift, organized a fundraiser, facilitated or attended a support group meeting, displayed your ITP awareness items, contacted the media, or sported purple for platelets, our ITP members and donors were a huge part of our success in making the world of ITP a more manageable place to be! One look at this "year in review" will reveal the significant impact of your support and involvement.

Even as we evolve and grow, we remain committed to the original values on which PDSA was founded: informed patients are in a better position to understand their disease, have more meaningful dialogue with their doctors, and potentially have an improved opportunity to heal. We are heartened by messages from our members indicating that our information and support have made a difference in their journey toward better health. Whatever role you play within this dynamic community, I hope you take pride in knowing that your personal efforts have made a difference and have helped to ease the burden of those living with this disease.

Thank you for all you do to contribute to our continued success.



Caroline Kruse
Executive Director



PDSA Advocacy Partnerships

NORD – National Organization for Rare Disorders
AARDA – American Autoimmune Related Diseases Association
A-PLUS – American Plasma Users Coalition
ASH – American Society of Hematology
CPAG – Coalition of Patient Advocacy Groups (NIH)
ICON – Pediatric ITP Consortium of North America
PPTA – Plasma Protein Therapeutics Association
IAPO – International Alliance of Patients' Organizations
FDA Alliance
Genetic Alliance
PBSA – Patients for Biologics Safety & Access

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

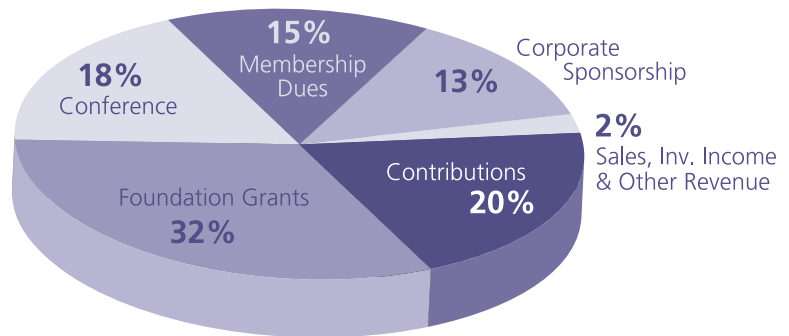
The Platelet Disorder Support Association is the leading ITP advocacy organization in North America. Each day, PDSA serves the worldwide ITP community of patients, practitioners, caregivers, advocates, and key disease stakeholders, promoting their needs and uniting them on a global level. We build awareness, educate the global community, and provide critical connections and resources that empower patients to take charge of their disease and encourage practitioners to exercise patient-centered medical care.

"We are so grateful to PDSA for their support and encouragement since the very beginning. It is because of their help that Lindsey finally found NPlate which has given her a "normal" life back.
330,00 platelets this week!
A long way from 0"
– Tammi C.

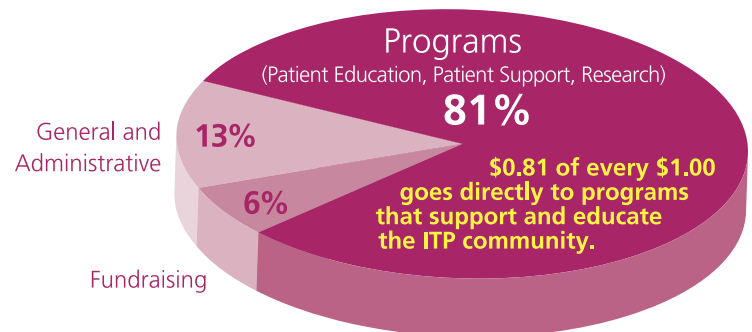


"I am one of the many that have ITP! I am so glad there is this page because I've been feeling like there is nothing out there and I feel alone!"
– Libbie G.

Income Funding

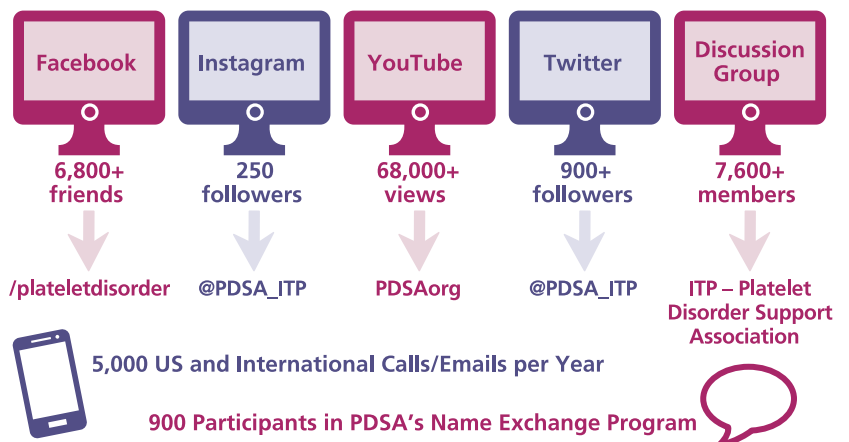


How The Funds Were Used



Awareness Reach & Social Media Growth

Social Networking



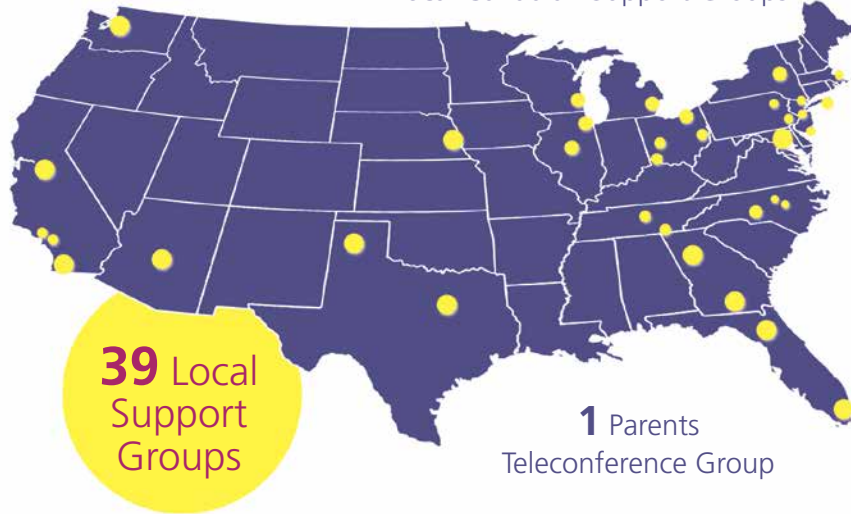
www.pdsa.org



Education & Support Program Highlights

1 Canadian Teleconference Group

2 Local Canadian Support Groups



1 Parents

Teleconference Group



Current ITP Support Group Facilitators and attendees interested in starting new groups attended the Facilitator Workshop at ITP Conference 2015 in Nashville, TN

2015 \$1,000 Audi Gerstein Scholarship Winner – Emily Harris

Westport, CT

Columbia University College of Physicians and Surgeons

"My experience as an ITP patient has made me keenly aware of the many implications of medicine beyond biology. After experiencing medicine as a patient, I have learned about both the medical profession and myself. I now personally understand the importance of kindness, compassion and communication in medicine. Patients are people, not illnesses. I fundamentally value the dignity and importance of every human life, no matter who the person is or what their background entails. It is for this reason that I plan to dedicate my career to improving lives."



"We are so thankful for these calls! They give us the opportunity to share our struggles and our victories, to ask questions and just know that we aren't alone."

I know my son LOVES the kid portion of the call. Thank you to Jay and the PDSA for making these calls happen."

– Jana R.



Six-year-old ITP patient, Joey, visits Oakland A's catcher Josh Phegley who overcame the same blood disorder

"Until I found your web site I was afraid and confused as very little information was out there on the subject. I found the information you sent informative and comforting it gave me a better understanding of what I was going through. Please keep up the good work and thank you."

– Isobel J.

25 Informational Booklets and Numerous Articles

(including Spanish, French, Finnish, and Chinese versions)



Quarterly Newsletters

Circle of Hope
and
The Platelet News



Monthly E-Newsletter

The Platelet News



Maddie is one of
38 children who are part of the
ITP Poke-R Club for Kids with ITP



38 children ages 2-15 enrolled in the ITP Poke-R Club



38 kits distributed, including Buzzy devices,
PD Platelet poker chips, and Poke-R-Club scorecards



38 prizes distributed equaling a total of 570 needle sticks

Community Events & Outreach Highlights



-  **15th** Annual Conference
-  **240** attendees
-  **\$10,800** in conference scholarships given to 24 attendees in need of financial assistance



-  **800** awareness bands distributed
-  **300** ITP awareness pins distributed
-  **110,000** people saw a PDSA Facebook post in the month of September



-  **6th** Annual Event
-  **5** locations
-  **340** participants
-  **\$63,873.81** raised for PDSA programs and research



Platelet Disorder Support Association

www.pdsa.org

-  **24** events
-  **32** event organizers
-  **\$44,521.58** raised for PDSA programs and research

"I was diagnosed in 1995. I found PDSA about 16 years ago online. Learned so much and such wonderful people. Started attending the annual conference then and started volunteering the very next year. So thankful I am able to help every year at the conference. PDSA is a blessing!!" – Sharon P.



Above: ITP kids and siblings had a great time at the Kids 'Purple Power' Camp at the ITP Conference including games and crafts, swimming, and even an indoor boat ride!



Above: Dr. David Kuter hosted a Jeopardy ITP game played by attendees at the outstanding ITP conference in Nashville, TN; Right: The 'Teens Only' session at the ITP Conference in Nashville was an amazing and fun experience



Above: More than 60 people took part in the first Hope for Hayley Pump It up for Platelets Walk/Run 5K event to raise ITP awareness and fundraise for PDSA; Right: ITP Warriors, Melissa Hilsabeck and Joey Fitzgerald share a laugh while pulling raffle tickets in Orange, CA



Above: Chicago Pump It Up for Platelets! volunteers celebrate another successful event; Left: Kristie Lyons, a NY teacher with ITP, raised ITP awareness through events at her school, a painting event, and her own '100 Mile Challenge'



Above: The entire staff of the Bleeding and Clotting Disorders Institute, including Director, Dr. Michael Tarantino (far L, back row) in Peoria, IL, helped spread ITP awareness on Sport Purple for Platelets Day

"My wife and I are parents of an adult child with ITP. If you can you should attend the PDSA Conference. It is well worth the time and \$\$, you get a wealth of information and meet some of the greatest people you ever will know. PDSA is one of the finest organizations I have ever had contact with. The doctors are on the cutting edge of ITP research and will sit down and talk to you on a one to one basis." – Steve G.

Advocacy & Research Highlights

Carol Hoxie, Communication Specialist, PDSA, met Kenya Mills, CEO of Innovative Infusions, while hosting the PDSA exhibit table at the IgNS 4th Annual Meeting, Sept. 2015 in Washington, DC



PDSA staff attended the following meetings:

- American Society of Hematology (ASH)
- Immunoglobulin Nursing Society (IgNS)
- 5th Intercontinental Cooperative ITP Expert Meeting
- National Summit on Autoimmune Disease
- NORD Rare Diseases & Orphan Products Breakthrough Summit
- Plasma Protein Therapeutics Association Stakeholders Meeting & Forum
- 8th Annual Rare Disease Day
- 4th World Orphan Drug Congress
- Role of Investigational New Drugs in Patient Care



ITP experts from around the world gather together for the 5th ICIS meeting in Switzerland. PDSA Executive Director Caroline Kruse is on the far right holding the Swiss flag

Contributions in 2015

Each year thousands of individuals, organizations, corporations and foundations help support PDSA through donations of gifts, tributes in memory or honor of family and friends, sponsorships of new programs and special events, and contributions to the annual fund. PDSA receives NO federal funding. Since 1998, it has been the caring members of the ITP community who have given life to PDSA's mission of helping children, adults and families affected by ITP and other platelet disorders. Every gift is important and deeply appreciated. The following list includes gifts received between January 1, 2015 and December 31, 2015.



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McKesson Foundation
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Microsoft
Pfizer Foundations Matching Gifts Programs
Progressive Casualty Insurance Company
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Schwab Charitable Fund
Wells Fargo Community Support Campaign



Circle of Hope (\$5,000+) Individuals

Madeline & John Hromyak
Emily & Kris Kile
Louise Kittel
Barbara & Peter Pruitt, Jr.
Steven Rodgers

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Kimberly & Rodney Hall
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Michael Tarantino, MD
Joyce & Dale Zimmerman

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Circle of Hope – Event Organizers

Pump It Up For Platelets!
Ashburn, VA – \$5,330
Kim & Bobby Moore – Organizers

Pump It Up For Platelets!
Ames, IA – \$2,511.35
Hayley & Nathan Shimanek – Organizers

Pump It Up For Platelets!
Chicago, IL – \$12,542.22
Susan Frank – Organizer
Trish & Paul Santaromana – Organizers
Emily Auterson – Team Organizer
Jennifer Slad – Team Organizer

Pump It Up For Platelets!
Everett, WA – \$6,741.40
Jenn & Andy Lindal – Organizers

Pump It Up For Platelets!
Orange, CA – \$4,480
Leilani de Castro – Organizer
Melissa Hilsabeck – Organizer
Angela Racoosin – Team Organizer

Pedal for Platelets!
El Tour de Tucson – \$14,290
Barry Deutsch – Organizer
Wanda Gregory – Organizer
Peter Pruitt, Jr. – Organizer
Michael Tarantino, MD – Organizer

Archer & Greiner – \$1,765
Stephanie Zane, Esq. – Organizer

Painting For Platelets – \$2,050
Tammi Cammauf – Organizer

Lagree Fundraisers – \$1,644.20
Paula Lagree – Organizer

July Challenge – \$2,318
Kristie Lyons – Organizer

Parents Partner for PDSA – \$1,900
Kim Barber – Organizer

New York City Half Marathon – \$3,408
The McGuirl Family – Organizers

Hamptons Half Marathon – \$3,771.10
Meredith Prescott – Organizer

Purple for Platelets Marathon – \$1,170.79
Kristin Hunt – Organizer

Tri-Beta Bio Honor Society/Lewis
University – \$1,032.50
Jennifer Roberts, PhD – Organizer

Hope for Hayley – \$1,510
Kimberly & Ron Sewald – Organizers

FastRuby – \$4,020
Jill & Matt Tillinghast – Organizers

Supporters (\$1,000+)

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**"Please accept my second contribution to your wonderful organization.
As an ITP patient in my first year of treatment, PDSA continues to be my anchor."
– Pitkin J.**

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Understanding ITP

ITP, immune thrombocytopenia, is an autoimmune disease. Platelets are targeted as foreign by the immune system and eliminated in the spleen, or sometimes the liver. Some ITP patients also have impaired platelet production. It is difficult to determine how many adults have ITP, so estimates vary. One study reports that the incidence of adult ITP (how many people get diagnosed each year) is from 1.64 to 6.65 per 100,000. The prevalence (how many adults have ITP at any time) is approximately 9.5 cases per 100,000, and affects all age and ethnic groups. Children comprise approximately half of all ITP cases. Normal platelet counts range from 150,000 to 400,000 per microliter of blood. People with platelet counts less than 10,000 have severe ITP. A count of 30,000 or higher is usually enough to prevent major bleeding. There is no cure for ITP, but there are treatments, all with different risks and benefits.

What our members are saying:

**"I have had ITP since 1997
and your association has been
the best support for me.
You have kept me sane."
– Penny R.**

**"I have Severe Refractory ITP.
Diagnosed at age 2 (two),
I will be 42 in July. I live with
platelet counts between 2,000
to 25,000. With PDSA I am
not alone anymore!"
– Michelle B.**



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