Dear Friends of PDSA,

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
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. 330,000 platelets this week! A long way from 0”
– Tammi C.

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– Tammi C.

How The Funds Were Used

$0.81 of every $1.00 goes directly to programs that support and educate the ITP community.

Awareness Reach & Social Media Growth

Social Networking

www.pdsa.org

www.pdsa.org

www.pdsa.org

www.pdsa.org

www.pdsa.org
**Education & Support Program Highlights**

1. Canadian Teleconference Group
2. Local Canadian Support Groups
39 Local Support Groups

**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.

“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.

Six-year-old ITP patient, Joey, visits Oakland A’s catcher Josh Phegley who overcame the same blood disorder
Maddie is one of 38 children who are part of the ITP Poke-R Club for Kids with ITP.
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

**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.

“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.
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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- Amgen
- CSL Behring Biotherapies for Life
- Emergent BioSolutions
- GE Foundation
- Birny Mason, Jr. Foundation
- McKesson Foundation
- Novartis
- Octapharma
- Option Care
- Rigel Pharmaceuticals

Matching Gift Companies

- AIG Matching Grants Program
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- Wells Fargo Community Support Campaign
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- Progressive Casualty Insurance Company
- Rockwell Automation
- 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

Circle of Hope ($3,000 – $4,999) Indiv.

- Anonymous
- Kimberly & Rodney Hall
- Karen & David Imig
- Mary Lou & James Lyons

Circle of Hope ($2,000 – $2,999) Indiv.

- Kenda & Brian Bamesberger
- Rachel & Patrick English
- Joan & Richard Jordan
- Michael Tarantino, MD
- Joyce & Dale Zimmerman

Advocacy & Research Highlights

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
Circle of Hope ($1,000 – $1,999)
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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 McGuir 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

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Bleeding & Clotting Disorders Institute
War Axe Bicycles

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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.