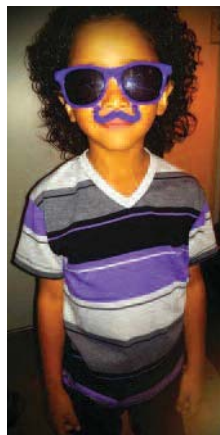




*for People with ITP*

## *2013 annual report*



*education. advocacy. research. support.*

## from the executive director



Dear Friends of PDSA,

2013 was a banner year for PDSA. We celebrated our 15th anniversary of making the world of ITP a more manageable place to be by providing an array of free education and support services to tens of thousands of people in more than 130 countries. Our ITP Conference 2013 was the largest to date, with 275 attendees. And on a day with record heat in our nation's capitol, PDSA took an historic first step to bring ITP awareness to members of the U.S. Congress. The 27 champions who took part in PDSA's first 'ITP Day on the Hill' met with 20 different congressional staff from 10 different states.



*ITP affects almost 10 times as many people as hemophilia*, yet most people know nothing about it. This lack of public awareness leaves many ITP patients feeling isolated and alone, and is the main reason why there is so little support for research on ITP and, therefore, the lack of advancement in treatment. This past year the PDSA and its network of volunteers served the greatest number of people with ITP in the history of the organization. We are proud of our many accomplishments through social media; public awareness initiatives; and increased engagement with patients, family members and the health care community. We achieved record-breaking visibility, yet we know there is still much work to be done.

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. We are truly grateful to those who make this possible every day — those who give their time, energy and resources to make a difference in the lives of people who struggle with ITP and other platelet disorders. One look at this “year in review” will reveal the significant impact of their support and involvement.

PDSA was founded on the premise that 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 continue to be true to our mission and are heartened by messages from our members indicating that our information and support have been helpful in their journey toward better health. Whatever role you play within this dynamic community, your efforts help to ease the burden of those living with this disease. More importantly, your support helps us travel down the road toward better treatments and the hope of a cure.

Thank you,

Caroline Kruse  
Executive Director

## 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.

## 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.



PDSA provided a wide variety of online and printed information to increase knowledge of ITP, treatments, and wellness practices.

## Newsletter

Our quarterly newsletter The Platelet News offered the latest research and recommendations for treatment and improved health for ITP patients. These issues included reports from our annual meeting, advocacy meetings, and annual hematology conferences. They provided updates on PDSA support groups around the U.S., fundraising news, patients' letters and stories, and other pertinent news.

## E-News

Our monthly complimentary online newsletter was distributed to more than 17,000 on our mailing list. Each issue summarized 8-10 recent, relevant news articles related to ITP or general health, and provided resources to patients and families.

## Patient Booklets

PDSA increased our educational booklet offerings in 2013 from 16 to 20 patient booklets, including nine of our most popular booklets available in Spanish and French. All of our booklets are distributed free at local support group meetings, medical meetings and conferences and are available by mail. Members are encouraged to take copies to their hematologists to reach ITP patients and increase awareness of ITP. PDSA also partnered with Health Monitor Network on our 5th patient Guide to ITP. Featuring an ITP patient on the cover and PDSA members throughout the Guide, 150,000 copies were distributed to medical institutions and hematology offices across the U.S.

## Web Site

Our Web site ([www.pdsa.org](http://www.pdsa.org)), with more than 200 pages of FREE information, was updated throughout the year with the latest research and news. During 2013, our Web site received about 30,000 unique visitors per month from 130 countries.

## Social Networking Sites

PDSA's social networking pages continue to grow in popularity. We now have more than 10,000 Facebook friends and Twitter followers. Our Inside Stories patient and medical expert videos have been viewed more than 12,000 times on YouTube and Vimeo.

"Thanks so much for the information and support on the site. I have been in the dark about all of this and it is a great relief to have some enlightenment." – Kristin K.

"I want to thank you for maintaining this FB page and especially the Web page. It helped me so much to understand more about ITP. My 3 ½-year-old daughter was diagnosed with ITP two months ago and since then I was drowning in an ocean of tears. Your information helps me to cope with this disease and to start to fight against it. Thank you again!" – Gopali D.

## PDSA 2013 affiliations

NORD – National Organization for Rare Disorders

ICON – Pediatric ITP Consortium of North America

AARDA – American Autoimmune Related Diseases Association

PPTA – Plasma Protein Therapeutics Association

A-PLUS – American Plasma Users Coalition

IAPO – International Alliance of Patients' Organizations

ASH – American Society of Hematology

FDA Alliance

CPAG – Coalition of Patient Advocacy Groups (NIH)

Genetic Alliance

## advocacy & research

At industry and government meetings, PDSA serves as the voice of the ITP community. It represents and shows the strength of our community. In 2013 PDSA achieved its goal of encouraging advocacy and research for the treatment of ITP and other platelet disorders in the following ways:

We participated in meetings of the American Plasma Users Coalition (A-PLUS), an organization devoted to assuring quality IVIg access for all who need it. In 2013 this group addressed and commented on the following issues: Essential Health Benefits, Affordable Care Act, Patients' Access to Treatment Act and the Helping Sick Americans Now Act. In addition, PDSA was part of an effort to pass the Medicare IVIg Act in Congress.

In January 2013, PDSA joined ICON (Pediatric ITP Consortium of North America), a newly formed organization composed of 27 top pediatric hematologists in the U.S. and Canada. ICON's mission is to advance clinical research and care in pediatric immune thrombocytopenia.



Dr. W. Keith Hoots of the National Heart, Lung and Blood Institute (NHLBI) discussed NIH funding and research for blood diseases at ITP Conference 2013

PDSA staff attended meetings of The American Society of Hematology, American Society of Pediatric Hematology/Oncology (ASPHO), American Autoimmune Related Diseases Association, Congressional Briefing on Women and Autoimmune Disease, National Coalition of Autoimmune Patient Groups, 6th Annual Rare Disease Day at NIH, Immune Deficiency Foundation (IDF) National Conference, Immunoglobulin Nursing Society (IgNS) National Conference, Insurance & Reimbursement Conference, U.S. Conference on Rare Disease and Orphan Products.



Participants (L to R) from the Maryland/DC/Florida/Virginia group: Stephanie Kaplan (ASH); Barbara Pruitt; Rep. Ileana Ros-Lehtinen, (R-FL 27); Mat Heyman; PDSA Communication Specialist Carol Hoxie; and Craig Kessler, MD

*"Thank you for representing and advocating for the ITP community!"*

– Chris Gary P.



Participants (L-R) from the Ohio/Arizona/Montana group: Barbara Hise; PDSA Board Member Jamie Harwell; Joan Young; Congressman David Joyce, (R-OH 14); Alan Lichtin, MD; PDSA Executive Director Caroline Kruse; and Ralph Hise

## meetings

To meet our goal of supporting the exchange of information between patients, researchers, physicians and other members of the wellness community, PDSA organized and hosted its 13th ITP Conference in 2013.

### Annual Conference

ITP Conference 2013 was held July 19-21 in Washington, DC and was attended by more than 275 patients, presenters and associates. Ten of the world's most renowned ITP clinicians and researchers presented programs and met in small groups or one-on-one with patients and caregivers. The conference offered an advocacy program for 20 Canadian patients, a special teen program was attended by 16 teens, and our first ever Kids Kamp was a big hit for children with ITP, their siblings and children of parents with ITP. The conference included a Saturday evening dinner program, family fun event with a live band, and a fundraising membership raffle. Twenty-five patients were given scholarships to attend the conference.

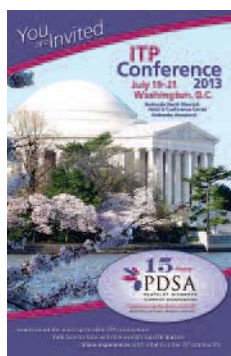
*"My favorite part of the conference was the additional children's programs and the video the kids/teens made.*

*It's so important for them to make connections and to have a voice.*

*Please continue with the children's programming. I loved the*

*'Coping with Chronic Illness' session."*

– Parent of child with ITP



Left: ITP kids enjoyed the first ever Kids Kamp at ITP Conference 2013; Right: At the 'For Teens Only' session at ITP Conference 2013, 16 teens created a new ITP Awareness video

In 2013 PDSA provided support services that promoted patient communication with other patients, physicians, and medical providers.

## Support Groups

PDSA's local support group program continues to grow each year with a total of 36 groups now actively engaged in major cities around the U.S. and in Canada. Our teleconference support group for parents of children with ITP celebrated its fourth anniversary with over 50 families participating and our teleconference support group for Canadian patients and family members continues to add more members.

*"Thank you. I wish I could adequately describe how helpful the PDSA Web site and local Atlanta support group have been. I am so grateful for all that you do and wish you every continued success." – Kathleen W.*

## Support Group Facilitators' Workshop

At its annual conference, PDSA offered a workshop for its group facilitators, who provide important non-medical assistance to ITP patients and their families.

## Online Discussion Group

PDSA provided online discussion groups for adults with ITP, teens with ITP, parents of children with ITP, and ITP and pregnancy. The site receives thousands of visits each day.

## Personal Counseling to Members and Non-members

Our staff responded to more than 1,000 emails, letters and phone calls requesting information and answers about platelet disorders.

## Name Exchange Program

We have more than 900 participants in our Name Exchange Program, developed for patients who want to communicate one-on-one with another patient.

## Audi Gerstein Scholarship

The PDSA's Audi Gerstein Scholarship Program provides financial assistance to senior high school students and college students who are suffering from ITP or a similar platelet disorder. In 2013 PDSA awarded its fifth \$1,000 Audi Gerstein Scholarship to a college student with ITP. Several other students received \$100 book awards.



*"I am eternally grateful for the day that I found PDSA online. After immediately creating an account, I found solace in the advice and sense of community on the discussion boards. When I attend college, I intend to major in chemistry and become a scientific researcher. I hope to return to my community as a wiser citizen with a stronger helping hand."*  
– Bethany Cucka, \$1,000 Audi Gerstein Scholarship winner 2013, Bristol, CT, Brown University



Above: Attendees of the 2013 Facilitators' Workshop heard tips from Dr. Robert Phillips on how to facilitate a support group; Below: The Cleveland ITP Support Group celebrated 10 years of patient support.



*"I just wanted to thank you so much for putting together the ITP Parents' call this evening. Not only did my husband and I find it really informative, it was helpful to hear from others who have been through the same things and have many of the same issues and questions. Most of all, it was wonderful for my son to talk to the other kids! He has had months of trying to explain to friends and classmates why he feels so tired and why he can't participate in some games and sports anymore. He has felt lonely and isolated. Tonight he was elated that he spoke to other kids who understood, and he can't wait for the next call."* – Jana S.

*"A few weeks ago, I went to the first Boston ITP support group. It was small but wonderful. Even though it was a 2.5 hour drive each way, it was well worth the effort to attend. I'm looking forward to the February meeting. I continue to be a grateful recipient of all the PDSA does. This support group is one small example of the many services you all provide. Thank You!"*  
– Dave N.

# awareness



"Wow, I am happy but I am also a little sad that PDSA has nearly 4,000 Likes now. The number keeps growing which is good for awareness, but also sad for me to see how many people are affected by ITP every day." – Becky M.

During the month of September we celebrated National ITP Awareness Month. ITP patients, family members, friends and our industry partners joined PDSA to raise public awareness of ITP. A number of activities moved us closer to our goal of increasing the public's understanding of ITP and other platelet disorders and communicating the important resources and support PDSA offers for ITP patients, families, and health care providers.

## Sport Purple for Platelets Day

The last Friday in September found people young and old, from schools to business offices, sporting shades of purple.

"We may be a small group, but we are mighty. Thank you for raising awareness!!!" – Amy G.



Above Top: Family all sport purple tee-shirts; Above: Dale Paynter with colleagues of Conestoga-Rovers & Associates, Ontario, Canada, on Sport Purple Day; Below: Kristin Hunt and McGill Univ. students sport purple.

## Awareness Materials

PDSA staff distributed more than 2,500 awareness bands, 2,500 ITP awareness pins, and more than 2,500 educational brochures, pamphlets and school information packets.

## International ITP Alliance

PDSA collaborated with European ITP patient advocacy groups to share ideas and strategies to foster greater awareness and understanding of ITP, a little-known disease around the world.

## PDSA Packets

More than 500 educational packets were distributed to hematologists and other medical professionals.

"I'm from Venezuela and I have ITP. This Web site is just fantastic. Soon I'll be a member." – Geraldine F.



Left: Shyill Ismail sports a beautiful purple gown for her wedding; Above: Stephanie Zane (3rd from R, front) and her colleagues at Archer & Greiner sport purple; Above right: The team at Amgen sports purple for platelets; Right: Child sports purple head to foot.



More than 200 people participated in the first Livingston, NJ "Pump it Up for Platelets!" event, increasing ITP awareness and raising over \$45,000.

During 2013 there were many outstanding fundraising events held that supported PDSA and helped raise awareness of ITP and PDSA, including:

### Pump it Up for Platelets

The 4th Annual Pump it Up for Platelets ~ for a World Free of ITP National Walk-Run took place in seven cities across the U.S. and Canada, raising more than \$78,000 for PDSA programs and research. First time events included Logan, IA, Poolesville, MD, "For the Love of Gracie" in Seattle WA, and the Livingston, NJ event which raised \$45,000 in its first year!

Many friends of PDSA held a variety of fundraisers, raising close to \$23,000 for programs and research: Archer & Greiner Law Firm Fundraiser, Conestoga-Rovers & Associates Fundraiser, Triathlon for Ayla Charness, Hope for Haley Benefit Ride, Lewis University/Tri-Beta Biological Honor Society, Montreal Half Marathon, Party for Platelets, Paula Lagree Dinner Party and BBQ, Pedal for Platelets: El Tour de Tucson, Showdown at Sundown, Time for Talon and Giving Tuesday.



PDSA Board Members Jamie Harwell and Peter Pruitt proudly show off their PDSA 'Pedal for Platelets' tee-shirts before cycling in the El Tour de Tucson.



Above: Melissa Hilsabeck (Fr, Ctr) with a great turnout for the Orange, CA walk-run; Right: Kaidan, ITP patient Ayla Charness' cousin, took part in a triathlon to raise funds for PDSA and awareness for ITP;



Below: Ocean Crist with PDSA Marketing Director, Nancy Potthast, and sisters Amanda and Ayla Charness at 'Time for Talon' fundraiser



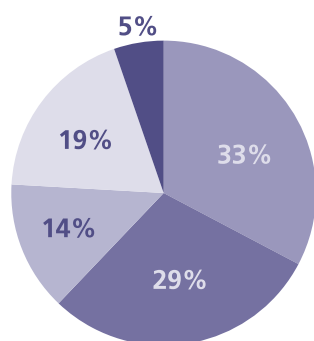
PDSA member Gen Kilianek (far right, 2nd row) and her family at Party for Platelets



At the first Poolesville, MD Walk-Run (L-R): Cindy Ayliff (Metro DC Support Group co-facilitator and Circle of Hope member), Cathy Brown (walk organizer, mother of Kelly Brown, and PDSA member and volunteer); Ryan K. (local child with ITP), and Kelly Brown (walk organizer, ITP patient, PDSA Circle of Hope member and volunteer.

"Something needs to be done!  
People need to know what this is and  
what it does to a person's life."  
— Meredith P.

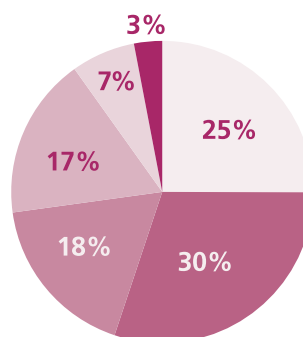
## ***schedule of functional expenses***



Patient Education	33%
Patient Support	29%
Programs	14%
General and Administrative	19%
Fundraising	5%



## ***income/funding***



Contributions	25%
Foundation Grants	30%
Conference	18%
Membership Dues	17%
Advertising	7%
Interest/Store and Other	3%

## ***contributions in 2013***

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, 2013 and December 31, 2013.

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**\$1000+**

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**AMGEN Canada**

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Massachusetts General Hospital | Boston, MA

**Howard Liebman, MD**

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**Drew Provan, MD**

Barts & The London Queen Mary's | London, UK

**John Semple, PhD**

St. Michael's Hospital | Toronto, Canada

**Michael Tarantino, MD**

The Bleeding and Clotting Disorders Institute | Peoria, IL

Emeritus | **Robert McMillan, MD**

Scripps Research Institute | La Jolla, CA

"My favorite part of the conference was the time that medical advisors spent with the folks and the level of caring that was shown; the concern to get to the bottom of this syndrome.

This year's conference increased my knowledge by making me feel like my challenges were not in my head and that they are shared with most ITP patients. Great job. Lots of hard work and it showed!"

– Adult with ITP



The doctors' panel at ITP Conference 2013 answers questions for attendees.

## ***PDSA 2013 staff***

**Caroline Kruse** | Executive Director

**Sara Armstrong** | Director of Administration

**Carol Hoxie** | Communication Specialist

**Grace Filani** | Administrative Assistant/Database Coordinator

**Marjorie Ligelis** | Chief Financial Officer

**Nancy Potthast** | Director of Marketing

**Meagan Richards** | Administrative Assistant

**Joan Young** | Founder



## *what our members say...*

"My daughter is Mia B.  
We are pretty set with info  
as I'm on the PDSA Web site  
all the time (hah!)  
and she's had ITP now for a year.  
Your Web site is a godsend.  
Thanks for all you do.  
It was Mia's choice to support PDSA...  
and I'm proud of her choice.  
THANK YOU." – Jennifer R.

"Thank you for all you do!  
My Grandson has ITP and the information  
you provide is priceless." – Sandie S.

"Great job, PDSA. Thanks a lot for bringing  
such a detailed guide along with inspiring,  
motivating and educational stories for  
ITP survivors like me. Amazing work...  
keep up the good job." – Sunny S.

"I was diagnosed with ITP a month ago.  
Your Web site is a goldmine  
of information... thank you!  
I just submitted my membership.  
Thank you." – Jana G.

"Thank you for all of  
the wonderful information.  
Coming from a mom of an 8-year-old girl  
who has been battling ITP for two years,  
I am grateful." – Andrea C.



*for People with ITP*

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