

Education.



Advocacy.



Research.



Support.



2012 Annual Report

From the Executive Director



Dear Friends of PDSA,

I feel lucky — it's been 10 years since my ITP went into remission. But talking with ITP patients through calls and emails to the PDSA office or at our local support group meetings, annual conference, or fundraisers reminds me how difficult life can be living with this illness. Their moving stories serve as inspiration to me, the PDSA Staff, Board of Directors, and Medical Advisory Board to continue to do more to support the ITP patient community and educate others about this complicated, challenging disease.

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 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 has never received any Federal funding. 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 of you who make this possible every day; know you are making a difference in the lives of people who struggle with ITP and other platelet disorders. The information you'll read in this Annual Report are just some of the highlights of 2012.

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

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.

"When I was first diagnosed with this illness last year I was confused and totally terrified not knowing what to think. I found your Web site and made several phone calls; your staff was so supportive and helpful. This was so important to me and provided a powerful connection at a time of such great distress." – Joanne O.

Mission

The Platelet Disorder Support Association is dedicated to assisting patients with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, and research.

Education

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. In 2012 we updated the look of our newsletter with a new layout, combination of colors and glossy paper.

■ **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 has produced 16 patient booklets, including five of our most popular booklets available in Spanish and French. This year we updated two of our booklets: "Health Insurance and Assistance Programs for ITP Patients" and "Coping with ITP" and translated the "Coping" booklet to Spanish. 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 3rd and 4th patient Guide to ITP. Featuring ITP patients 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), with more than 200 pages of FREE information, was updated throughout the year with the latest research and news. Our 'Complementary Treatments' section of the Web site was revised to include resources and links to evidence-based research studies. Our 'Other Platelet Disorders' section was also updated. During 2012, our Web site received about 25,000 – 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.

PDSA 2012 Affiliations

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)

PPTA – Plasma Protein Therapeutics Association

IAPO – International Alliance of Patients' Organizations

FDA Alliance

Alliance for BioTherapeutics

Genetic Alliance

"My daughter and I read each issue of The Platelet News with great interest. Since her diagnosis with ITP several years ago, we have taken great comfort in the publications PDSA has to offer and so appreciate all the information they provide."
– Donna and Emily G.

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 2012 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 2012 this group addressed and commented on the following issues: **Essential Health Benefits, Affordable Care Act, Patient Access to Treatment Act and the Helping Sick Americans Now Act.**



PDSA's Executive Director, Caroline Kruse and Director of Marketing, Nancy Potthast attended the first Thrombosis & Hemostasis Summit of North America meeting in Chicago, IL

■ PDSA staff attended meetings of **The American Society of Hematology, American Autoimmune Related Diseases Association, National Coalition of Autoimmune Patient Groups, Immunoglobulin Nursing Society, Thrombosis & Hemostasis Summit of North America, National Heart, Lung, and Blood Institute 13th Annual Public Interest Organization Meeting, and the Plasma Protein Therapeutics Association's 20th Anniversary Gala and Plasma Protein Forum.**

■ Funded **Phase I of an Etiology patient survey and study** looking at the potential causes of ITP.



Dr. Robert Phillips and PDSA Communication Specialist Carol Hoxie at the Congressional Hearing on Autoimmune Disease

Meetings

"My most favorite part of the conference was the teen group — hearing their perspective on living with ITP." – ITP Patient

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 12th ITP Conference in 2012:

■ **Annual Conference** – ITP Conference 2012 was held July 20-22 in Denver, CO and was attended by more than 220 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



There was a great turnout for the Teens Only session with Dr. Tarantino at ITP Conference 2012 in Denver

and caregivers. The conference offered an advocacy program for 20 Canadian patients and a special teen program was attended by 20 teens. Two new programs were offered this year: "For Kid's Only" and "Know Your Rights in the Era of Healthcare Reform." The conference included a Saturday evening dinner program, family fun event with a live band, and a fundraising membership raffle. Twenty-three patients were given partial or full scholarships to attend the conference.



In 2012 PDSA provided support services that promoted patient communication with other patients, physicians, and medical providers.

Support



Support Group Facilitator's Workshop

"ITP can be a huge blessing...if you let it be that. It can give you a sense of depth and clarity you wouldn't otherwise have. It makes it crystal clear what's important. And I've been able to relate to people at a level I never could have before being diagnosed. When I walk out of the meeting, I feel better enabled to deal with ITP."

– Tom Langer, WI ITP Support Group Member

■ **Support Groups** – PDSA's local support group program continues to grow each year with a total of 34 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 two-year anniversary with over 50 families participating and we added a teleconference support group for Canadian patients and family members.

■ **Support Group Facilitator's 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.



Megan Roberts, \$1,000 Audi Gerstein Scholarship Winner 2012. Megan is attending Endicott College in Beverly, Massachusetts and is majoring in nursing.

■ **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 2012 PDSA awarded its fourth \$1,000 Audi Gerstein Scholarship to a college student with ITP. Several other students received \$100 book awards.

"It does not do one any good to dwell on the difficult time, or the unknown. I realized that my regrets were just decisions that did not go the way I had planned, but everything happens for a reason. The most important thing I have learned from this difficult time is to take one day at a time and live each of those days like it is your last."

– Megan Roberts

Audi Gerstein Scholarship winner

ITP Poke-R-Club Program



Poke-R-Club program kit

PDSA is helping to take the 'ouch' out of frequent blood tests for children and teens with ITP through our new Poke-R-Club program, which was piloted this year in four locations: Children's Hospital, Boston; Denver Children's Hospital; Rady Children's Hospital, San Diego; and The Bleeding & Clotting Disorders Institute, Peoria, IL.

Awareness

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** – September 28th found people young and old, from schools to business offices, sporting shades of purple.



"Thank you for being there! I have benefited so much from your site, and I am happy to spread awareness of not only ITP, but your wonderful services."

– Rebecca D.



■ PDSA staff distributed more than 2,000 awareness bands, 550 ITP awareness pins, and more than 2,300 educational brochures, pamphlets and school information packets.



PDSA Executive Director Caroline Kruse (front, 2nd from right) joined members from European ITP patient support groups, including Germany, Finland, Sweden, the Netherlands and the UK, at the ITP Support Association's Annual Convention held in York, UK

■ **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.

■ Distributed over **500 educational packets** to hematologists and other medical professionals.

"Kelly's school has been so supportive of Kelly and her ITP. Today many of the students dressed in purple in Kelly's honor and tonight's football game has the theme to dress in purple for Kelly and to spread ITP awareness.

The students are also writing ITP across on their inner arm where blood would normally be drawn."

– Cathy B., mom of Kelly

Fundraising

During 2012 there were many outstanding fundraising events held that supported PDSA and helped raise awareness of ITP and PDSA, including:

■ **Peak Performance for Children** – This two-day event to benefit PDSA took place on August 24 and 25 in Kansas City, MO and included a cocktail party with a silent and live auction, a 5k fun run, hole-in-one contest and Kansas City B-B-Q. The event raised more than \$80,000 for PDSA programs and research.

■ **Pump it Up for Platelets** – The 3rd Annual **Pump it Up for Platelets ~ for a World Free of ITP** National walk/run took place in eight cities across the U.S. and Canada, raising close to \$66,000 for PDSA programs and research.

■ Many friends of PDSA held a variety of fundraisers, raising thousands of dollars for programs and research: **Leah Dryden School Fundraiser, Elizabeth Smith Fundraising Dinner & Chinese Auction, Archer & Greiner Law Firm Fundraiser, Conestoga-Rovers & Associates Fundraiser, Sara Armstrong and Barbara Pruitt Jewelry Fundraisers, Ayla Charness School Fundraiser, Giving Tuesday, and Pennies for Platelets.**



ITP Patient Leila and a friend raise "Pennies for Platelets" at a Walgreens in NJ

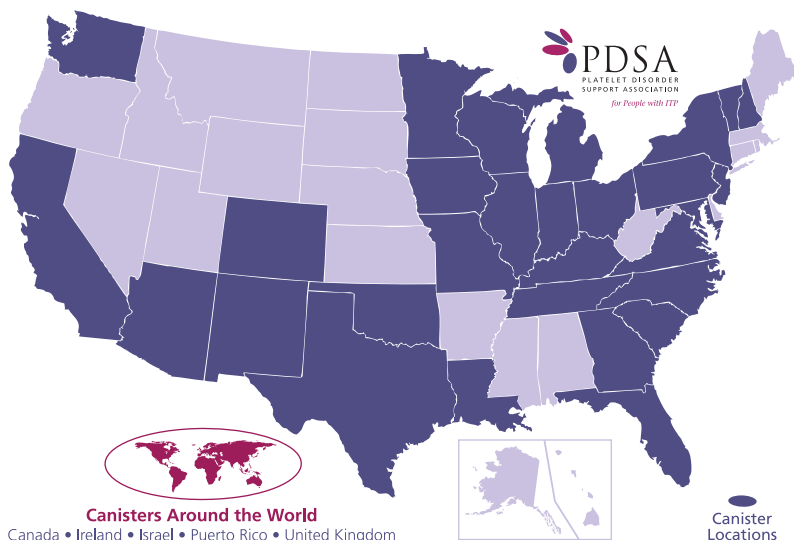


Over 100 participants took part in the Basking Ridge, NJ Pump It Up for Platelets Walk-Run in June



The 2012 Peak Performance team

Pennies for Platelets



St. Lambert, Quebec Pump it Up for Platelets organizer Kristin Hunt (3rd from right) with her father – Robin, mother – Karin, brother – Justin and the platelet pals



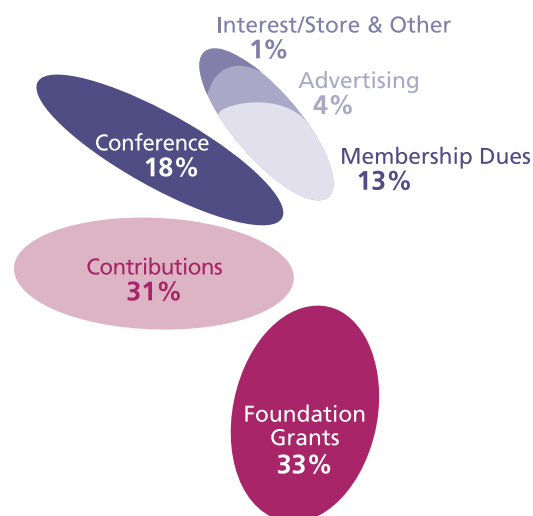
Fullerton, CA Pump it Up for Platelets organizer Melissa Hilsabeck and supporters from the local fire department

Schedule of Functional Expenses

Fundraising	4%
General and Administrative	16%
Programs	80%
• Patient Education • Support • Awareness • Advocacy • Research	



Income/Funding



Contributions in 2012

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, 2012 and December 31, 2012.

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"Keep the wonderful panel of doctors — they are so compassionate and thoughtful in responding to the various patients' questions. Q & A is always a great part of the symposium. Bless you for all you do for us." – ITP Patient



PDSA's Medical Advisory Board members joined PDSA Board Chair Peter Pruitt, and PDSA Executive Director Caroline Kruse, for a luncheon at the 2012 ASH Meeting in Atlanta, GA (L to R: John Semple, PhD., Douglas Cines, MD, James Bussel, MD, Caroline Kruse, Terry Gernsheimer, MD, Craig Kessler, MD, Howard Liebman, MD, David Kuter, MD, Peter Pruitt, Andra James, MD, and Michael Tarantino, MD)



The doctors' panel at ITP Conference 2012 answers questions for attendees



PDSA Board Members and Staff (Back row L to R: Sara Armstrong, Peter Pruitt, Kim Everett, Caroline Kruse, Carol Hoxie, Meagan Richards, Jay Charness, Marjorie Ligelis. Front row L to R: Nancy Potthast, Karen Avrick, and Diane Joseph)

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"The PDSA Web site and conferences were such a big part of my journey with ITP that I want to give back to PDSA so that others will continue to have the benefits that it provides. The articles, message boards, and newsletters always gave me new things to think about and discuss with my doctor.

The first conference that I went to was the first time I didn't feel alone in having ITP.

That is why I donate money to PDSA." – Megan R.

"This organization has really made a difference in helping me cope with my daughter's ITP and it helped me understand the treatments and side effects far better than I could have done through research or relying on the doctor's information alone.

My daughter has had this 5 ½ years now, but is doing well, thanks to the research that finds newer treatments." – Pauline D., mom of Caitlin

"I cannot stress how much your Web site has provided me with the vital information that I needed to assist and reassure my sister and her husband through this medical crisis.

Organizations such as the pdsa.org are the beacon of hope that people in distress desperately need.

I cannot thank you enough." – Renee F.



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