



for People with ITP



2011 ANNUAL REPORT

EDUCATION.
ADVOCACY.
RESEARCH.
SUPPORT.

FROM THE EXECUTIVE DIRECTOR



Dear Friends of PDSA,

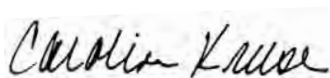
2011 was an outstanding year for the Platelet Disorder Support Association.

We received the designation for National ITP Awareness Month and our collective efforts raised awareness around the U.S. and the globe. We hosted our 2nd annual National walk/run more than doubling our efforts from the prior year and coordinated numerous fundraising events raising over \$180,000 for PDSA programs and research. We added four new booklets, increased our local support groups to 32, and hosted our 11th annual ITP conference with 220 attendees. We updated our Web site and participated in several research projects and advocacy campaigns. Throughout all of this activity, PDSA maintained contact with thousands of patients and families in 130 countries, answering individual questions and creating communication links through our name exchange program, support groups, active discussion group, and social networking sites.

All these accomplishments were made possible by individual and corporate contributions and the help of our dedicated volunteers, staff, Board of Directors, and Medical Advisors. In the years since my own diagnosis, I have been continually amazed by the many ways in which people reach out to help our community. While PDSA was founded by ITP patients for ITP patients, we have grown and are now comprised of an incredible variety of people who work to advance our cause in a myriad of ways. I personally thank all who gave their time and resources to help improve the lives of the people we serve.

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 has been helpful in their journey toward healing. 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.

In Gratitude,



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 1.6 4 to 6.6 5 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.

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.
- **E-News** – Our monthly complimentary online newsletter was distributed to more than 15,000 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.
- **New Patient Booklets** – PDSA produced a new patient booklet "ITP and the Female Lifecycle: Bleeding Issues in the Stages of a Woman's Life". We also created French versions of two patient information booklets, "ITP in Adults: Frequently Asked Questions" and "ITP in Children: Frequently Asked Questions." These three new booklets, as well as our 11 other 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 a patient *Guide to ITP* with 150,000 copies distributed to medical institutions and hematology offices.
- **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 including an ITP Early Detection and Prevention page. A new section was created for the national walk/run, *Pump it up for Platelets!* to make it easier for organizers and participants to share information about their event with family and friends. During 2011, our Web site received about 30,000 – 40,000 visits per month.
- **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 2011 AFFILIATIONS

NORD – National Organization for Rare Disorders

PPTA – Plasma Protein Therapeutics Association

AARDA – American Autoimmune Related Diseases Association

IAPO – International Alliance of Patients' Organizations

A-Plus – American Plasma Users Coalition

FDA Alliance

ASH – American Society of Hematology

Alliance for BioTherapeutics

CPAG – Coalition of Patient Advocacy Groups (NIH)

Genetic Alliance

SUPPORT

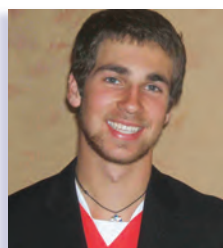
In 2011 PDSA provided support services that promoted patient communication with other patients, physicians, and medical providers.

- **Support Groups** – PDSA's local support group program continues to grow each year with a total of 32 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 one year anniversary with over 40 families participating.
- **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.



Linda McGuirl (right),
Co-facilitator Central North
Jersey ITP Support Group and
co-organizer Basking Ridge, NJ
"Pump it up for Platelets"
walk/run

"Since I have lived with ITP since 1985 I felt that I could help other people who had the same disease, I wanted to help people realize that they can live a happy life with ITP. Even with my very low counts, I managed to have 3 healthy children with the help of my doctors and the support of my family. I wanted to share my success story with others."



**2011 Audi Gerstein
Scholarship winner
Dean Freundlich**

- **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 2011 PDSA awarded its second \$1,000 Audi Gerstein Scholarship to a college student with ITP. Several other students received \$100 book awards.

"I cannot stress how much your website 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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Director of Development

Marjorie Ligelis
Chief Financial Officer

Meagan Richards
Administrative Assistant

Sara Armstrong
Director of Administration

Carol Hoxie
Communication Specialist

Nancy Potthast
Director of Marketing

Joan Young
Founder



AWARENESS

2011 was an amazing year for PDSA as patients around the U.S. and around the world joined together to raise public awareness and create a better understanding 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:



Ayla Charness (front left, with her parents and sister) – ITP patient for seven years

2011 Children's Miracle Network Colorado Champion

"In Washington, DC I met my Congressman and talked about getting help for people with ITP. He told me it was difficult, but that he thought I could do anything I put my mind to. It was the best year ever."

- **National ITP Awareness Month** – PDSA received the designation of September as National ITP Awareness Month and inclusion on the National Health Observances Calendar resulting in media coverage across the globe with 17 newspaper articles including stories in the UK and India; four TV feature stories, and interviews including Fox, CBS, and NBC.



- **Sport Purple for Platelets Day** – September 30th found people young and old, from schools to business offices, sporting shades of purple. Even the national TV news show, *Fox & Friends*' anchors Sported Purple for Platelets on September 30th.

- In September the PDSA staff distributed more than **2,000 "Got Platelets?" awareness bands, 550 ITP awareness pins, 23 school information packets, and 2,300 educational brochures and pamphlets.**
- **International ITP Website Alliance** – PDSA partnered with European ITP patient advocacy groups to develop an International ITP Web site offering patients and healthcare professionals information in various languages: <http://itpsupport.eu/>
- Attended and presented a PDSA exhibit booth for **Cytopenias & Hemostasis in 2011** in Chicago, IL and the **American Society of Hematology (ASH) Meeting and Exposition** in San Diego, CA.
- **Guide to ITP** – Partnered with Health Monitor Network to develop a comprehensive patient *Guide to ITP* with **150,000 copies distributed** to medical institutions and hematology offices.



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



MEETINGS

"My favorite part of the conference was spending the weekend with fellow ITPers."

Having had ITP for 4+ years and never met anybody with this, you have no idea how much this meant to me!"

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 11th ITP Conference in 2011:

- **Annual Conference** – Our PDSA 2011 Annual ITP Conference was held July 8-10 in Boston, MA and was attended by more than 220 patients, presenters and associates. Nine 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. For the first time our conference offered an advocacy program for 20 Canadian patients. A special teen program was attended by 20 teens. The conference included a Saturday evening dinner program, family fun event with a live band, and a fundraising membership raffle. Twenty-two patients were given partial or full scholarships to attend the conference.

The 'Teens Only' session at the Annual Conference with Dr. Tarantino



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 2011 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 2011 this group addressed and commented on the following issues: **Essential Health Benefits, Affordable Care Act, MSM Blood Donor Deferral Policy, Biovigilance, Medicare IVIG Access, and Specialty Tier Pricing.**
- We served on the planning committee for the **National Institutes of Health (NIH) 12th Annual Public Interest Organization (PIO) Meeting** and was one of only two organizations (out of 94 PIO groups) asked to present at the meeting. PDSA Executive Director Caroline Kruse joined NIH Director of the Office of Dietary Supplements, Dr. Paul Coates, and gave presentations on "Dietary Supplements".
- PDSA staff attended meetings of the **American Autoimmune Related Diseases Association**, the **Social Security Administration's Compassionate Allowances Hearing on Autoimmune Diseases**, the **National Institute of Environmental Sciences Health Meeting**, the **4th Annual NIH Rare Disease Day**, the **National Organization of Rare Disorders FDA Meeting for Patient Organizations**, and the **Plasma Protein Therapeutics Association Stakeholder Intake Meeting.**
- Funded **Phase I of an Etiology patient survey and study** looking at the potential causes of ITP.



Caroline Kruse was an invited speaker at the NHLBI PIO Meeting



The Peak Performance team of volunteers managed events that raised over \$80,000 for PDSA and ITP



FUNDRAISING

During 2011 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 September 16 & 17 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 2nd 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 \$90,000 for PDSA programs and research.



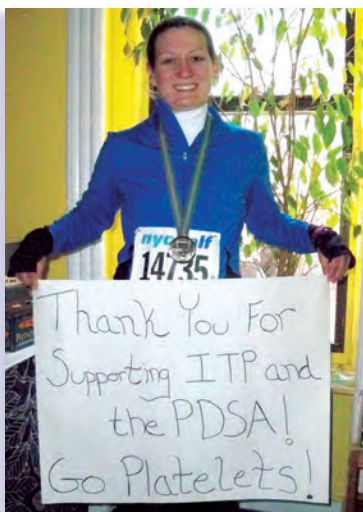
"I am so glad to have been a part of PDSA's first national walk/run in support of ITP, and I hope that all of our efforts will help to make other patients' lives that much better, as PDSA has done for me these last 6 years."



Organizers of a Wisconsin 5K (L to R) Ann Sarnowski, Kim Everett, and Trudy Sensat along with volunteers, sponsors, and participants outdid themselves, raising over \$14,000 in support of PDSA!



Kristen Hunt (third from left), ITP patient and college student, organized an outstanding walk event in St. Lambert, Quebec, Canada on September 11, 2011, raising over \$10K for PDSA!



Elizabeth Smith took to the streets of NYC in support of ITP.

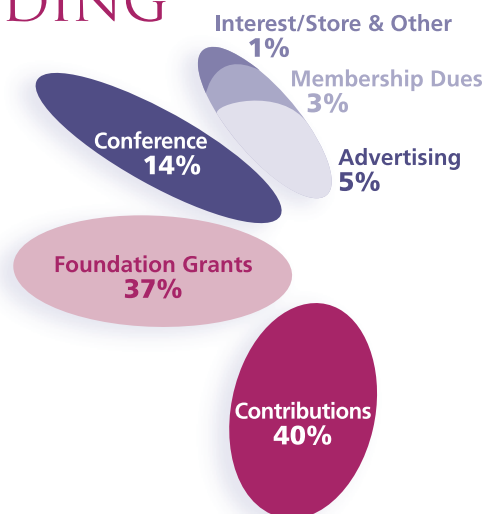
- **True Sport Giveback Challenge** – College student Kristin Hunt, organizer of our Quebec walk/run, created an inspiring video "Pump it up for Platelets" using photos from her event. Out of six finalists, Kristen's video won first place and \$7,500 for PDSA.
- Many friends of PDSA held a variety of fundraisers, raising thousands of dollars for programs and research: **Leah Dryden School Fundraiser, Elizabeth Smart NYC Half Marathon, Archer & Greiner Law Firm Fundraiser, Conestoga-Rovers & Associates Fundraiser, Sara Armstrong and Barbara Pruitt Jewelry Fundraisers, Ayla Charness School Fundraiser, PDSA Awareness Band fundraiser, Chicago Marathon, and the Kruse Birthday Bash Fundraiser for PDSA.**

"...We spent hours, days and weeks researching the Internet, connecting with doctors and hospitals, exploring alternative health options (you know the story) ... but more than anything, it was your association, your magazine, your articles that provided guidance and peace of mind. Thank you." ~Gail

SCHEDULE OF FUNCTIONAL EXPENSES

| | |
|---|------------|
| Fundraising | 11% |
| General and Administrative | 23% |
| Programs | 66% |
| <ul style="list-style-type: none"> • Patient Education • Support • Awareness • Advocacy • Research | |

INCOME/ FUNDING



CONTRIBUTIONS IN 2011

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, 2011 and December 31, 2011.

FOUNDATIONS AND CORPORATE SUPPORT

Amgen
Amgen Canada
Baxter Healthcare Corporation

CSL Behring
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PDSA Board Chair, Peter Pruitt, and wife Barbara Pruitt, Circle of Hope Members. Barbara is a former PDSA Board Chair and current facilitator of the Miami ITP Support Group.

"I can't explain how wonderful it was to actually connect with someone else with ITP. After 40 years I had stopped looking. But to talk to someone else who had walked in your shoes...I was elated!"
~Barbara Pruitt



The doctors' panel at the 2011 ITP Conference answers questions for attendees

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Robert McMillan, MD | Scripps Research Institute | La Jolla, CA



PDSA's Medical Advisory Board members joined PDSA Board Chair, Peter Pruitt, and PDSA Executive Director, Caroline Kruse, for a luncheon at the

2011 ASH Meeting in San Diego, CA (L to R: Dr. John Semple, Dr. Robert McMillan, Mr. Peter Pruitt, Dr. Howard Liebman, Dr. Douglas Cines, Dr. Terry Gernsheimer, Dr. David Kuter, Dr. Andra James, Dr. James Bussel, Mrs. Caroline Kruse, Dr. Michael Tarantino, and Dr. Craig Kessler)

WHAT OUR MEMBERS SAY...

"I can't tell you how much you and your organization have helped me this year! I just hope there is more awareness of ITP. Your organization has been the only one that truly gave me strength this year!"

"Attending this year's conference gave me a deeper knowledge of ITP; provided support; awareness of updates, including medications and new treatment; very helpful. What a tremendous contribution aid, and educational opportunity for an ITP audience. Unique and singular — nothing like it."

"Thank you so very much, and for all that the PDSA does. It was so helpful to us when our daughter was diagnosed 5 years ago. It continues to be a wonderful source of information for us and for the people in our lives that want to know more about ITP."

"In the few weeks since my daughter's recent diagnosis of ITP, I have found your organization and your website tremendously informative and reassuring. Thanks for all you do!"

MISSION

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



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PDSA is a 501(c)3 organization.
All contributions are tax deductible.