The Platelet News
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PDSA
PLATELET DISORDER SUPPORT ASSOCIATION

Enhancing the lives of patients with ITP and other platelet disorders

INSIDE THIS ISSUE

Research Highlights from ASH Annual Meeting

The American Society of Hematology's annual meeting brings together thousands of physicians, researchers and industry personnel to share the latest research on blood disorders. From the thousands of abstracts published or presented at the meeting in December, we've culled those we thought would be of interest and summarized them in this article.

We're often asked, "What is the latest research?" There's no better place to answer that question than the ASH abstracts and presentations.

The abstracts are printed in full in the journal *Blood,* Vol. 108, Issue 11, Nov. 16, 2006, and are available online at *http://www.bloodjournal.org*

Quality of Life (QoL)

A NEW QUESTIONNAIRE

Researchers from Amgen, Weill/Cornell Medical Center, the University of Oklahoma and Scripps Research Institute devised and tested a quality of life questionnaire specifically for ITP patients. The 44-item questionnaire, called the *(continued on page 4)*

ITP Sessions Pull In Crowds at Hematology Meeting

Joan Young

Hundreds of people scrambled to fill the chairs in the large auditorium. When the seats were filled, the ushers stopped the crowds that gathered outside the room from filling every inch of floor space and creating a fire hazard. Those who remained outside stood in line until someone left the auditorium or stood tall to try to see through the doorway.

Was this a rock concert? No. It was a session at the American Society of Hematology meeting, Dec. 9-12, featuring presentations on the latest research on ITP. Hard to believe.

Most of the excitement was generated by promising news from clinical trials of treatments that stimulate the bone marrow to produce more platelets. These treatments, AMG531 (a subcutaneous injection from Amgen) and Promacta (eltrombopag, a pill from GlaxoSmithKline), mimic thrombopoietin, the protein in blood that stimulates bone marrow to make platelets. Research shows that many people with ITP have a platelet-production problem in addition to a platelet-destruction problem, so helping the body make more platelets is one way of raising the platelet count. *(continued on page 3)*

Message from the President

"The only thing constant in life is change" wrote François de la Rochefoucauld.

It has been change that has characterized the past few months at PDSA.

Many of you know or have spoken with Albert (Buzz) Fries at our conferences, regional meetings or during phone calls. He will be leaving PDSA in mid-April. Buzz has played an active role in many aspects of the organization—from tracking our finances to editing our newsletter. His departure has prompted some changes that will streamline the organization.

To assume Buzz's financial tasks, we have hired a chief financial officer, Marjorie Ligalis. We contracted an editor, Sandy Graziano, to help us with our newsletter and other publications. The next position to fill is a communications specialist, a person who will help develop and manage the content of our booklets and Web site and become our resident expert in ITP and other platelet disorders. Splitting Buzz's multifaceted role among staff will allow for a more logical division of labor and create positions that reflect specific responsibilities.

Meanwhile, Alice Baer, our administrative director, is continuing to assume some of the tasks that I have been doing, as well as taking on tasks that Buzz used to handle. She now has more responsibility for updating our online store, sending periodic guestbook mailings and creating conference materials. Sandy Ashton, our administrative assistant, has been busy answering the mail and sending materials to those who request information. Mary Ann Kibarian, PDSA's director of development, is managing the fund-raisers, local groups and general flow of memberships.

When the dust settles from all the changes, we'll be able to publish newsletters on time (apologies for the delay in this issue), share more information, and have an organization that will be poised for a new level of commitment and growth. I look forward to increasing our ability to assist those in need.

Joan Young, Founder and President
Platelet Disorder Support Association

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ITP Sessions Pull In Crowds at Hematology Meeting

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Line forms for entry to the ITP presentations.

In addition to ITP, the thrombopoietin treatments may also be very useful in raising the platelet count of people with low platelets due to chemotherapy, liver disease or progressive bone marrow failure. Amgen and GlaxoSmithKline are seeking approval from the Food and Drug Administration so these treatments can be made widely available.

While this session was "standing room only," others, in much larger rooms, were also filled. During one Friday afternoon symposium, "Eighth Annual Review of Immune Thrombocytopenic Purpura: ITP Guidelines" sponsored by Baxter, Dr. James Bussel led a session reporting on the progress of an international team of 14 ITP researchers on developing strategies for treating ITP Treatment philosophies for ITP have evolved since the publication of the 1996 ASH Treatment Guidelines. The British Society for Haematology published guidelines in 2003 reflecting the treatment philosophy in the United Kingdom, which sometimes differs from practice in the United States. Gaining an international ITP treatment consensus, while ambitious, would be very helpful in raising awareness of the latest research and practice philosophies.

At the same time, and next door to the "Eighth Annual Review" session, Dr. David Kuter chaired the symposium, "Thrombocytopenia in the practice of hematology and oncology: focus on increasing platelet production" sponsored by Amgen. When the Friday symposia schedule was published, I and others felt that holding two thrombocytopenia symposia at the same time would dilute attendance at what historically was one very popular session. This didn't happen. Both sessions were crowded, speaking to the interest in this important subject.

PDSA will continue to follow research throughout the year. Several other companies are initiating clinical trials in thrombopoietic agents. The international group developing guidelines will publish some of their initial findings. As new research directions unfold, we will be sure to tell you about them in our newsletter and in e-news.

Right: Board Chair Barbara Pruitt assists at the PDSA booth during the American Society of Hematology Meeting in December.

Research Highlights from ASH Annual Meeting

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ITP patient assessment questionnaire (ITP-PAQ), assesses symptoms, bother, fatigue, activity, fear, psychological health, work, social activity, women's reproductive health and overall QoL. Based on two studies of the ITP-PAQ, one in 73 patients, the other in 35 patients, the authors determined that their results provide preliminary evidence of the reliability, validity and responsiveness of the ITP-PAQ. (ab 1078)

The same researchers used the ITP-PAQ in patients taking a long-term course of AMG 531, Amgen's drug that stimulates platelet production. The study included 36 patients (25 female, 11 male; 29 white, 6 Hispanic, 1 black), with an average age of 50. The majority (8 of 10) had had their spleen removed before the study. All patients had completed a previous AMG 531 study. The ITP-PAQ has 10 scales: four on physical health (symptoms, fatigue, bother and activity), two on emotional health (psychological and fear), three on quality of life (overall, social and work), and one on women's reproductive health. Each scale is scored 1 (worst) to 11 (best). Analysis occurred at week 1 (pretreatment) to week 24. Results linked treatment with improvement (in the range of 7.4 to 9.4 points) in symptoms, fatigue, bother, and activity, and work-related quality of life. Patients with a durable platelet response versus those without a durable response showed a trend toward greater improvement in all 10 scales. (ab 3292)

BURDEN OF ILLNESS

Researchers from Georgia Cancer Specialists and GlaxoSmithKline conducted a retrospective longitudinal study of ITP patients to characterize the burden of chronic ITP among adults. The study evaluated long-term claims data from health plans from four regions of the United States. Of 22 million current active enrollees in these health plans, 3,743 adult chronic ITP patients were identified and included in the study. Two-thirds of those patients were 50 or older; about half were male and half female. Slightly less than half of the patients received outpatient medication, the vast majority of which was oral corticosteroids (91%). Other first-line drug treatments included IVIg (2.6%) and Anti-D (1.4%). Second-line therapies were cyclosporine (3.8%), mycophenolate (3%), azathioprine (2.6%), danazol (2.4%) and cyclophosphamide (0.9%). There were 1,077 inpatient hospitalizations in which ITP contributed to the stay, with a median cost of $3,115 per admission. Drug-treatment costs ranged from $12 for oral corticosteroids to $19,050 for IVIg. Slightly less than 10 percent of patients underwent whole blood transfusions (median cost $552), and 2 percent had platelet transfusions (median cost $402). The authors concluded: "These data support the need for safe and effective treatments for adult patients with chronic ITP to reduce the incidence of costly hospitalizations, transfusions, IVIg infusions and splenectomy." (ab 3291)

OUTCOMES MEASURES IN CHILDHOOD ITP

Researchers from Ottawa, Canada, assessed the relationship between bleeding severity and quality of life. Ninety children with ITP were enrolled at six North American centers. Children 7 and older self-reported their QoL scores, and parents of younger children reported scores on

(continued on the next page)

Quotes from the Friday Symposia at ASH

"The absence of detectable autoantibody in many ITP patients suggests the presence of alternative platelet destruction mechanisms."

"In adults, recent studies have shown an annual incidence of 1.6/100,000, an increase in incidence with age, and a female predominance in middle-aged patients only."

"…Though ITP is fifty- to one hundred-fold less common than incidental thrombocytopenia of pregnancy, it is the most common cause of isolated thrombocytopenia during the first trimester."

"Studies from Japan and Italy have clearly demonstrated that *Helicobacter pylori* infection can be associated with the development of ITP. … Since testing for *H. pylori* is noninvasive and since treatment has few side effects, routine screening for *H. pylori* in newly diagnosed patients with ITP is recommended."

"…Many subjects with genetic thrombocytopenias are initially misdiagnosed with ITP and receive therapies that are not only useless but also dangerous."

"The clinical management of … ITP is still based on anecdotal evidence, small descriptive series of patients, and only [a] few controlled studies. Due to these limitations, it has been difficult to establish accurate treatment of ITP."

"The problem of thrombocytopenia is particularly acute in the context of MDS [myelodysplastic syndromes] because MDS patients often have coexistent functional platelet defects that contribute to bleeding."

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Quotes from the Friday Symposia at ASH

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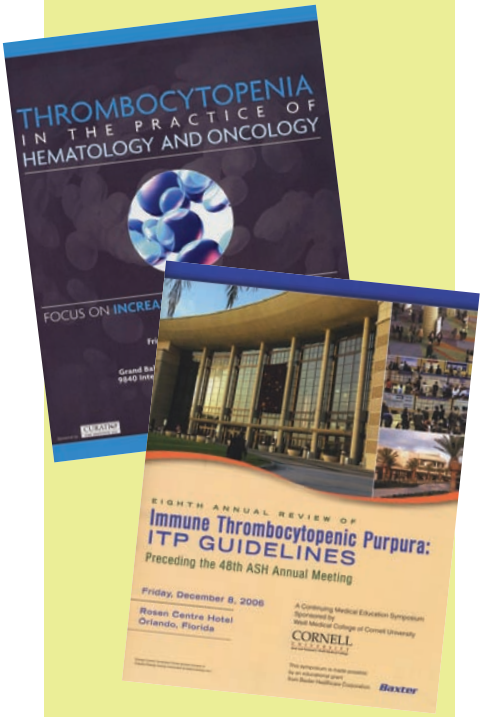

"The majority of children diagnosed with … ITP can expect a spontaneous resolution within six months and often within six weeks. The literature suggests that eventual normalization of the platelet count happens regardless of the chosen management."

"The inherited thrombocytopenias are rare disorders whose study has provided important insights into the regulation of platelet production in human subjects."

"Thrombopoietin levels are normal or only modestly increased in patients with ITP, in contrast to the tenfold increase in patients with aplastic anemia."

"Of the second-generation thrombopoietic growth factors, only AMG531 and eltrombopag have been tested in human diseases. Both increased the platelet count in patients with ITP and could do so for an extended time without apparent untoward effects."

Research Highlights from ASH Annual Meeting

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behalf of their child. Parents reported their own QoL as well. In both the case of proxy reporting and self-reporting, bleeding severity did not correlate strongly with QoL experience of either the child or parent. The authors wrote: "These results indicate that many factors in addition to bleeding signs may impact the children and parents, such as anxiety about the disease, length of hospital stay, frequency of visits to the physicians' office, and medication side effects." They suggest that multiple outcome measures are needed to understand the full spectrum of ITP's impact. (ab 1079)

Treatment

ANTI-D

Today, both anti-D immune globulin and intravenous immune globulin (IVIg) are established treatment options for children and adults with ITP. Yet national shortages of IVIg exist. Because the efficacy of the two treatment options are considered similar, and because severe adverse events are rare with both, researchers at the University of Illinois College of Medicine compared the costs of anti-D and IVIg as initial treatment in patients that do not require emergency treatment for their ITP. Patients in the study were children and adults who were Rh positive and had not had their spleens removed. In three separate analyses, anti-D therapy was substantially less costly than IVIg therapy. (ab 3305)

Based on a study of five children with chronic ITP, researchers in Turkey concluded that anti-D is a "valuable, safe, well-tolerated and cheap alternative to conventional chronic ITP treatments in selected non-splenectomized patients." The young patients had not responded to steroids or high-dose IVIg. They received a single intravenous dose of anti-D and were monitored for response to treatment and adverse events up to 28 days after infusion. Two of the five patients experienced an elevation in platelet count. Mild headache, fever and chills occurred in one patient, which was ameliorated with prednisone and acetaminophen. (ab 3967)

Anti-D produces a rapid rise in platelets, but the duration of response is short (median 46 days). More than half of patients treated intermittently with anti-D continue to require therapy after one year. Researchers from St. Luke's Roosevelt Hospital Center and Beth Israel Medical Center, both in New York City, tested whether adding danazol to anti-D might enable a longer duration of response. Both drugs are alternatives to spleen removal. In a single arm, nonrandomized phase 2 trial, patients received daily danazol plus anti-D on day one, to be repeated whenever platelet count falls below 30,000/uL. Of 26 patients planned for recruitment, seven have enrolled to date. Two were removed from the study due to danazol toxicities; both have maintained platelet counts higher than 30,000/uL. Three patients had sustained responses at 14 to 35 weeks followup. One of these patients required a second course of anti-D at 40 weeks followup. No treatment-related deaths occurred. (ab 3983)

After reports linking anti-D immune globulin with rare observations of hemoglobin in the urine, due presumably to intravascular hemolysis *(continued on the next page)*

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(bursting of red blood cells releasing hemoglobin), researchers at the Comprehensive Bleeding Disorders Center in Peoria, Ill., reviewed data from a recent prospective randomized trial they had completed in children with newly diagnosed ITP. Children in the clinical trial had received either anti-D once or IVIg once. None of the patients had frank blood in the urine following treatment, but hemoglobin concentration declined more in the anti-D group than the IVIg group. Pretreatment analysis of urine revealed that 24 of 91 patients had at least trace blood in the urine. Patients were less likely to experience an increase in their platelet counts if red blood cells were present in their urine before treatment began. (ab 1088)

IVIG

A group from Spain and Russia tested safety and efficacy of IVIG31 Grifols, a human intravenous immunoglobulin, in patients diagnosed with chronic ITP. The agent is a close formulation to a similar agent by Grifols, Flebogamma, in clinical use since 1992. There are differences in the purification process of the two agents.

The open, prospective study was nonrandomized. Nineteen patients with chronic ITP (at least six months after diagnosis) in acute phase were treated with IVIG31 Grifols for five consecutive days. Fourteen patients responded to the study drug. The median time for platelet response was ≤ 2.5 days, and the median number of days the platelet count remained at efficacy endpoint was ≥ 7 days. For 17 patients, a regression of bleeding episodes was reported on day 14. Eight patients experienced adverse events related to the study drug; 16 were considered mild and five moderate. (ab 3956)

Pretreating mice with IVIg-primed white blood cells offers up to 50 percent longer duration of protection from a low platelet count (thrombocytopenia) than standard therapies with IVIg or TER-119 (a monoclonal antibody that reacts with red cells), according to a study by researchers in Canada. However, by day 12, none of the therapies offered protection against low platelet count. They are now testing IVIg-primed dendritic cells from bone marrow. (ab 703)

University of Utah scientists reviewed the cases of 40 patients who received IVIg plus platelet transfusion due to low platelet count. Platelet counts rose from an average 10,000/uL before treatment to 55,000/uL after 24 hours and 69,000/uL after 48 hours. After 24 hours, almost two-thirds of patients had a platelet count greater than 50,000/uL. Bleeding was controlled initially in all patients, and those requiring a procedure experienced no bleeding complications. More than half of the patients required additional treatments, and one-third underwent splenectomy. The response rates for three different IVIg products were similar, and elderly patients had equivalent benefit with no increased side effects (12 percent of patients were older than 80). (ab 3972)

After studies in mice indicated that ITP that involves autoantibodies against GP1b may be less responsive to IVIg treatment, researchers in Wisconsin reviewed the clinical histories of ITP patients who had undergone *(continued on the next page)*

Other Studies of Interest

Many more studies were presented at the ASH meeting. Below is a list of nine studies, not reported in the cover story, that relate to ITP.

1. An unusual form of immune thrombocytopenic purpura characterized by a platelet activating IgG antibody, ab 1086.

2. A mechanism of exacerbation of chronic ITP by infection: toll-like receptor 4 (TLR4) activation enhances antibody-mediated platelet phagocytosis by human macrophages, ab 480.

3. Profile of cell-derived microparticles (C-MP) in ITP: red cell microparticles (RMP) correlate with severity of ITP, ab 1087.

4. Predicting clinical outcome in patients with idiopathic thrombocytopenic purpura based on bone marrow clot CD20+ lymphocytes, ab 3954.

5. Prevalence estimate of idiopathic thrombocytopenic purpura (ITP) in the United States, ab 3955.

6. Bone marrow reticulin in patients with immune thrombocytopenic purpura, ab 3982.

7. Murine model of fetal and neonatal alloimmune thrombocytopenia mediated by anti-GPib· versus anti-,3 integrin antibodies, ab 704.

8. Insights into therapeutic mechanisms: measuring immature platelet fraction (IPF) describes response to treatment in immune thrombocytopenic purpura (ITP), ab 1070.

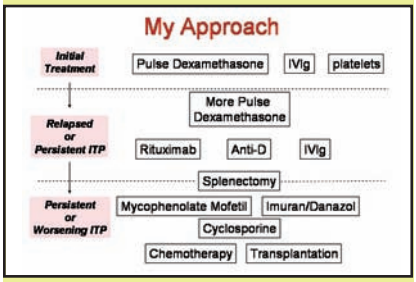
9. Gene expression profile of idiopathic thrombocytopenic purpura (ITP) reveals elevated expression of interferon-regulated genes, ab 702.

Orlando Regional Meeting

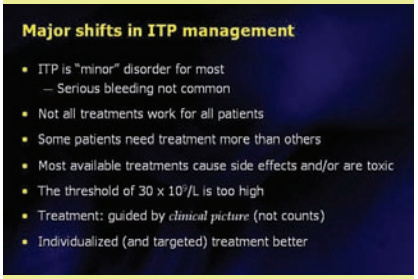
In conjunction with the American Society of Hematology meeting, PDSA held a Regional Meeting on December 7.

Dr. Patrick Fogarty, Assistant Professor of Medicine at the University of California, San Francisco spoke on "New Directions in Treatment of ITP in Adults" and Dr. Drew Provan, Senior Lecturer in Hematology at Bart's & The London, Queen Mary's School of Medicine and Dentistry in London, UK, spoke on "ITP Treatment Guidelines."

PDSA thanks Drs. Fogarty and Provan for speaking at the meeting and Amgen, Baxter, and GlaxoSmithKline for their support of our Regional Meetings through unrestricted educational grants.



Selected slide from Dr. Fogarty's presentation



Selected slide from Dr. Provan's presentation

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platelet autoantibody testing and received IVIg. They found 17 patients who received IVIg and had a platelet autoantibody test performed. Twelve of those patients had idiopathic ITP, meaning the cause was unknown. Of the remaining patients with autoantibodies, the researchers noted a significant difference in IVIg response among those with different autoantibodies. This small study supports the hypothesis that ITP involving anti-GP1b may be less responsive to IVIg, but the researchers call for larger, confirming studies. (ab 3987)

SPLENECTOMY

The following studies are aimed at building a case for avoiding splenectomy or reducing its negative impact.

Researchers at Mount Sinai School of Medicine in New York City, Cancer Care Centers of South Texas and Amgen, retrospectively reviewed a database of patients on 82 different managed-care plans to evaluate the costs of corticosteroid use and splenectomy in adults with ITP. Evaluating the records of 770 patients with ITP, the researchers concluded that patients who undergo splenectomy had care costs of *(continued on the next page)*

Dr. Drew Provan discusses the differences in treating ITP in the United States and the United Kingdom during PDSA's regional meeting in Orlando.

Audience members listen to a presentation at our Orlando Regional Meeting in December.

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more than twice that of patients who don't have their spleens removed. Patients with splenectomy incurred an average annual cost of care of $48,424; non-splenectomized patients incurred annual costs averaging $23,420. Corticosteroid use went up after splenectomy as well. In this population, 82 percent of patients took corticosteroids, and 12 percent of patients had splenectomy. (ab 5536)

In India, researchers seeking a way to treat ITP patients in their developing country observed the impact of dapsone on 46 consecutively treated patients. Steroid therapy had already proved ineffective for these patients. In 36 of the patients, purpura, or bleeding in the skin, disappeared and platelet counts rose significantly. The drug was continued for these 36 patients for an average 32 months, with no adverse effects. Splenectomy was successfully avoided in these patients. When treatment was intentionally withdrawn from 12 responders, platelet counts dropped for all. The researchers consider dapsone a cost-effective way to avoid splenectomy. They recommend that "all patients be started on dapsone once they fail to show response to steroids. Splenectomy should be reserved for patients who do not respond to dapsone." (ab 1073)

Belgian researchers reviewed the impact of laparoscopic splenectomy in 33 patients treated between 1998 and 2006. ITP was one of several reasons these patients might have undergone spleen removal. They found laparoscopic splenectomy to be safe and minimally invasive. However bleeding complications can occur, requiring close monitoring. (ab 5523)

A group at the University of Miami may have found a reason why bleeding complications occur with splenectomy. Comparing splenectomized patients with healthy individuals, they found that the spleen clears cell-derived microparticles, which are released during death of platelets, leukocytes, endothelial cells and red cells. These microparticles are high in splenectomized patients and may contribute to increased risk of blood clots. (ab 1482)

RITUXIMAB

Rituximab is widely used in autoimmune conditions, including ITP. This year's studies indicated its effectiveness in ITP and provided evidence for specific dosing regimens.

Two studies reviewed the short- and long-term efficacy of rituximab in patients with ITP. The first (ab 478) by French scientists, assessed whether rituximab is an alternative to splenectomy in chronic ITP. There were no controls in this study. The researchers evaluated 60 adults at multiple centers in an open-label, single-arm phase 2 trial. Rituximab offered a significant and durable response, enabling avoidance of splenectomy, in 40 percent of patients.

The second study (ab 479), from Weill Medical College of Cornell University and Italian researchers, analyzed data on 31 patients whose response to rituximab lasted more than one year. Responses lasting 2.5 years were seen in 17 of those patients. Other studies indicate that approximately one-third of ITP patients treated with rituximab have a response to treatment lasting more than one year.

A meta-analysis of 15 studies involving adults with ITP *(continued on the next page)*

Clusters of ITP

We occasionally hear reports of an unusually high number of ITP cases in a particular area. ITP is a rare disease, so it is important to investigate the potential cause if there are multiple cases diagnosed within a small population. Here's one example along with a reporting strategy.

QUESTION:

"We live in a very small town, but it is near a nuclear plant that utilizes our local lake. I thought ITP was rare, but just from personal experience I know of eight kids off the top of my head in our little town who have had ITP recently. Another child, a 6-year-old, was diagnosed yesterday and is getting IVIg today. Do you know the typical "distribution" of ITP in a population? Who would know if this is something we should be concerned about?"

ANSWER:

The reports of possible clusters should be made to the local public health department. If the health department determines that an investigation is warranted, it may involve the Centers for Disease Control and Prevention (CDC).

Disease clusters are the responsibility of the Agency for Toxic Substances & Disease Registry. The following link might be helpful for you, as well as provide information on investigations into disease clusters:
http://www.atsdr.cdc.gov/HEC/CSEM/cluster/evaluating.html

The responsibility for cancer clusters has been assigned to the National Center for Environmental Health:
http://www.cdc.gov/nceh/clusters/faq.htm

The authors concluded that hepatitis B blood screening should be done before rituximab therapy occurs because of the increased risk of acute hepatitis and liver failure.

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taking rituximab found an overall response rate of 55 percent; 38 percent of patients achieved a platelet count of at least 100,000 to 150,000. The authors call for prospective trials to further validate these results and identify ITP patients most likely to respond to rituximab. (ab 1076)

In an effort to reduce treatment costs, Japanese scientists reported on their efforts to give just one dose of rituximab to five patients with ITP who had not responded to other treatments. This is instead of the more common four weekly doses. All five patients responded to the single dose, although the length of response is unclear. A similarly small study by researchers in Italy (ab 3979) observed 14 patients given four weekly doses of rituximab. Half had an early response, and the response persisted in five patients. Side effects were not serious. Greek researchers presented three cases of relapsed and resistant ITP (ab 3968) that was treated with rituximab. Each has had a strong response to rituximab.

Combining rituximab with cyclophosphamide and dexamethasone resulted in long-lasting response in patients with chronic lymphocytic leukemia who had either hemolytic anemia or ITP, according to scientists at Long Island Jewish Medical Center in New Hyde Park, N.Y. (ab 2832). Three of the 18 patients had ITP. All patients responded with increased platelet counts, lasting for an average of 22 months. Nine patients relapsed, but when retreated, responded again.

Because hepatitis B can be reactivated with rituximab therapy, researchers in Detroit studied the incidence of hepatitis B reactivation with this treatment in 456 patients treated between 1998 and 2004. The authors concluded that hepatitis B blood screening should be done before rituximab therapy occurs because of the increased risk of acute hepatitis and liver failure. Further studies were suggested.

RITUXIMAB IN CHILDREN

A single-center study in India examined rituximab use in children with chronic ITP and Burkitt's lymphoma. Three children with ITP, whose disease had not responded to IVIg, steroids or other treatments, received rituximab at this center to avoid splenectomy. All three patients had platelet response; two had durable response of more than 12 months. The authors warn that patients should be "monitored for acute reactions, late-onset neutropenia, and long-term effects on brain with white matter changes." (ab 3892) Researchers in the United Kingdom reported three cases in which rituximab reversed cytopenia (low blood-cell counts) in children with autoimmune cytopenias due to an underlying immunodeficiency state, such as HIV. (ab 3977)

CORTICOSTEROIDS

Researchers at Amgen, Mount Sinai School of Medicine, and Hematology, Cancer Care Centers of *(continued on the next page)*

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South Texas analyzed a large database of managed-care patients to determine the complications related to corticosteroid use in patients with ITP. Compared with age and gender-matched individuals without ITP, those with ITP taking corticosteroids had higher risk for osteoporosis, diabetes and hypertension. The risk increased with longer steroid use. (ab 3295)

A TNF INHIBITOR

Enbrel is an inhibitor of tumor necrosis factor (TNF). It is a protein that blocks the action of a substance in the body that makes TNF. Researchers at the Comprehensive Bleeding Disorders Center in Peoria, Ill., and Children's Hospital of Orange County in Orange, Calif., conducted a pilot study of Enbrel in 16 patients with ITP. There was no comparison group. The authors wrote: "Although the precise mechanism of action is unclear, etanercept (Enbrel) treatment led to at least a partial platelet response in 50 percent of patients with persistent ITP and was well-tolerated." (ab 1075)

H. PYLORI

As in previous years, *H. pylori's* role in ITP was explored. *Helicobacter pylori (H. pylori)* is a bacteria that causes inflammation and ulcers in the stomach and can be eradicated with antibiotics. Researchers from Japan enrolled 35 adult patients with chronic ITP; 24, or 69 percent, were infected with *H. pylori*. Antibiotic treatment was effective for all patients with *H. pylori* infection, and about half of those patients also experienced a significant increase in platelet count. The researchers determined that *H. pylori* infection plays a role in ITP by altering the balance of certain immune system receptors (called FCgamma IIA and IIB) in favor of receptors that activate the immune system. (ab 1082) A study from China (ab 1084) also indicated that *H. pylori* eradication may improve platelet counts in some chronic ITP patients.

QUESTIONS ON STANDARD OF CARE

Scientists at Harvard and Tufts universities reported on two elderly patients whose ITP resolved within three months with no treatment. They note that the American Society of Hematology recommends urgent treatment of adults with platelet counts lower than 20,000. They advise that the risks and benefits of treatment be considered. (ab 3959)

A review of charts from 86 patients with chronic ITP from across the United States gave a sense of the current standard of care. Prednisone alone was given to 70 percent of patients as initial therapy, and 22 percent received prednisone plus IVIg. Just seven patients received a different initial therapy, such as prednisone plus danazol, WinRho, or prednisone plus WinRho. In both groups, two-thirds of patients needed a change in therapy. Half of patients had a splenectomy within one year after diagnosis. (ab 3990)

Treatments in the Pipeline

Several new ITP therapies are being tested, most of which aim to increase platelet count.

In a study in healthy volunteers, the company AkaRx of Paramus, N.J., tested the ability of its experimental drug, AK-501, to increase platelet count. AK-501 is an oral thrombopoietin (TPO) receptor agonist that stim- *(continued on the next page)*

Children with a rare genetic syndrome called velocardiofacial syndrome (VCF) are at risk of immune attacks on their blood cells, including an autoimmune disorder called Evans Syndrome, in which the body makes antibodies that destroy the red blood cells, platelets and white blood cells.

Research Highlights from ASH Annual Meeting

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ulates platelet production. With both single dose and multiple doses over 10 or 14 days, platelets increased more than 50 percent in a very high percentage of volunteers, and no serious adverse events were observed. (ab 477)

Amgen's drug, AMG 531, which also targets the TPO receptor, was evaluated in an open label study in ITP patients who have completed a previous AMG 531 study. This was a multicenter study involving researchers and scientists from the United States, Europe and Amgen. Of 36 patients in this part of the study, 30 had had a splenectomy. Some patients had serious treatment-related adverse events. Twenty-seven patients completed 48 or more weeks of therapy. Six of 12 patients taking corticosteroids were able to discontinue use. (ab 476)

North Carolina-based GlaxoSmithKline and international colleagues reported on a phase 2, randomized, double-blind, placebo-controlled study of eltrombopag (also a TPO agonist) in adults with chronic, previously treated ITP and platelets of less than 30,000. The 117 patients randomly received a placebo or one of three different doses of the oral drug. Responses increased with increasing dose. Bleeding incidents appeared to decrease at the two higher dose levels. A phase 3 study has begun (ab 475).

Scientists at Genzyme Corp. tested GMA 161, a humanized version of a monoclonal antibody against FCgamma-RIII that was in clinical trials in the 1980s. A low dose was tested in four patients, two of whom experienced short-lived increases in their platelet counts. The sponsor plans to test higher doses and repeated dosing. (ab 1074)

In ITP, platelets are destroyed by a process called phagocytosis. Protalex, a biotechnology company with headquarters in New Hope, Pa., used a test tube assay to determine whether its drug, PRTX-100, inhibits phagocytosis of platelets. It did. They report that a phase 1 study in healthy volunteers has also shown the drug is generally safe and well-tolerated. More studies are needed. (ab 1081)

Although many drugs are being tested that stimulate thrombopoietin (TPO), a colony-stimulating factor that stimulates the production of blood cells, especially platelets, researchers from Japan have presented a study that suggests the formation of platelets may not be regulated by TPO. Instead, they suggest platelet formation is regulated by some proplatelet formation stimulating factors. (ab 1112)

Diagnosis

Several studies aimed at improving the diagnosis of ITP and distinguishing ITP from other, similar diseases were presented.

Children with a rare genetic syndrome called velocardiofacial syndrome (VCF) are at risk of immune attacks on their blood cells, including an autoimmune disorder called Evans Syndrome, in which the body makes antibodies that destroy the red blood cells, platelets and white blood cells. Patients with VCF may experience negative effects with prolonged steroid therapy and should instead receive rituximab to boost their platelet count, according to researchers from Weill Cornell Medical College and Columbia College of Physicians and Surgeons. The authors discuss *(continued on the next page)*

Research Highlights from ASH Annual Meeting

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the difficulties of diagnosing this rare disease. (ab 3986)

A review of platelet count measures taken for 1,158 patients in Brazil using automatic blood counters suggested to the researchers that low platelet counts diagnosed by automated machines should be confirmed by slide exam and antiplatelet antibody to rule out thrombocytopenia of unknown cause or normal values when making a diagnosis of ITP. (ab 3966)

Meanwhile, Korean researchers were able to use measurement of immature platelet fraction (IPF) to distinguish patients with falling platelet counts (for example, due to chemotherapy or aplastic anemia), destruction of platelets (as in ITP), and platelet count problems due to cirrhosis of the liver. IPF equals the percentage of reticulated platelet over total platelet count. (ab 3950) Japanese investigators also found IPF to be an effective measure for distinguishing ITP from myelodysplastic syndrome. (ab 1085)

In a study of patients with chronic lymphocytic leukemia (CLL) at the Mayo Clinic (ab 2789), 47 percent of the CLL patients who also had autoimmune diseases causing low blood counts had ITP. This was a population of primary early stage CLL. A higher proportion than expected had ITP, which usually showed no symptoms. Italian researchers reported on 60 patients with CLL who developed autoimmune ITP (3.5 percent of all CLL patients in three centers over 10 years). Mean overall survival was 57 months. Patients with CLL and ITP had an unexpectedly short survival regardless of the fact of their early stage of CLL at diagnosis. (ab 4932)

University of Cincinnati scientists reported on a single patient, 18-year-old male, who had infectious mononucleosis with a severely low platelet count. Platelet antibodies were found, which has only been reported in two other cases. The patient was treated with prednisone and IVIg. (ab 3976)

Another potential diagnostic measure, the presence of antiphospholipid antibodies (APA), was tested in newly diagnosed ITP patients in France. The researchers found only 25 percent of patients had APA and determined that systematic testing is not warranted. (ab 1083)

Finally, Japanese researchers explored a link between leptin (a hormone produced by fat cells) and ITP. In three patients with menstruation-related cyclic low platelet counts, they found high levels of leptin in the serum as platelet counts dropped, suggesting that leptin may play a role in the form of ITP associated with menstruation. (ab 3985)

Note: This report is not sponsored or sanctioned by, nor a part of, the Annual Meeting of the American Society of Hematology (ASH), and ASH does not endorse any uses of this report.

Want to Meet Others?

Join our Name Exchange Program.

For more information see *www.pdsa.org/nameex.htm* or call us at 1-87-PLATELET

In Memorium

We received contributions between Oct. 1, 2006, and Dec. 31, 2006, in memory of:

Norma Amende
Toby Ann Handelman
Margaret M. Long
Blanche Walters

We appreciate their friends and family thinking of us in their time of grief.

If you are considering a memorial donation, please contact us at PDSA, P.O. Box 61533, Potomac, MD 20859 or at *pdsa@pdsa.org* or call toll-free 1-87-PLATELET, (877) 528-3538.

In Honor

We received contributions between Oct. 1, 2006, and Dec. 31, 2006, in honor of:

Jessica Cohen

If you are considering an honorarium donation, please contact us at PDSA, P.O. Box 61533, Potomac, MD 20859 or at *pdsa@pdsa.org* or call toll-free, 1-87-PLATELET, (877) 528-3538.

Matching Grants

We received donations and pledges (Oct. 1, 2006, through Dec. 31, 2006) from the following individuals through corporate matching gifts programs:

Diane Alaggia, *Pfizer*
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April 2006 HYL2154a

Baxter

What Our Friends Are Saying

HERE IS A SAMPLING OF NOTES RECEIVED RECENTLY.

Dear Joan Young, PDSA,

I've been with PDSA now since 2002. I have had ITP for about six years and only one time has it gone into remission—for only about two months, then it was back. I really think it has a lot to do with stress. I also have heart problems. It's very hard to get alternative medication because of the situation I'm in, being incarcerated. I've only been on prednisone the whole six years now. But, I will only take 5mg, no more than that, because I'm really scared of that medication because I had about all the side effects. I had depression so bad I cut myself back in 2002. That's why I only take 5mg now.

Well, I'm writing to you because I wanted some information about that book PDSA was coming out with, about people with ITP, their stories. I really would like to get it and need to know how much it costs. Please let me know. Without all your help, I probably would have died, so I greatly appreciate everything you all do. Thank you so much for your time.

Sincerely,
James

Dear PDSA,

After many years of slowly declining platelets, my red and white cell counts began to go down also.

A third bone marrow biopsy was ordered in July 2005—this time at a teaching hospital in Milwaukee. The slides were read at the University of Nebraska, and I was diagnosed with myelodysplasia in all three blood lines.

I'm now subscribing to the AA&MDS newsletter but will always be grateful to your organization for the helpful information I received from you.

The newsletter is outstanding! Pat yourselves on the back for jobs that are being done very well indeed!

Sincerely,
Carol

Joan,

It was nice talking to you today. God bless you for your work in forming the PDSA organization and offering so much resource information to all ITP sufferers. Thanks for putting out the alert on Rituxan. I would be very interested in finding out if there are other members in our Northern California area. Please let me know, as I may be interested in starting a chapter here one of these days.

Sincerely,
Ann

Dear PDSA,

This thank you is for Joan Young, Barbara, Buzz and everyone else I met at the ITP mini-seminar held in Orlando. My wife and I attended the Thursday event with doctors Provan and Fogarty. I want to say thank you to all who put this on. While it was a sobering talk (still no cure, still very few safe treatments, very few researchers in ITP, etc.), I just want to say thank you. My 10-year struggle with ITP has mostly been shrouded in mystery. Is it dangerous or a nuisance? *(continued on the next page)*

President's Circle

It's wonderful that 29 good souls have joined the President's Circle since its inception last summer. Circle membership represents all walks of life and all stages of the illness. Some still actively have ITP, others are in remission, and some are friends or family of patients or former patients. We are ever grateful that there are so many who are able and willing to help us at this generous $1,000 donation level.

We invite all who are interested in becoming more involved in supporting PDSA to join the President's Circle. The advantages of this membership level are many. Circle members have the opportunity to:

- Meet privately with the President and Board at the Annual Conference
- Meet with scientists and doctors at the conference and at regional meetings
- Attend a briefing by the PDSA leadership about PDSA's future plans
- Participate in forums to offer suggestions to enhance PDSA's work
- Receive news of the latest developments in the President's Circle Newsletter
- Receive free registration at the annual conference

We hope more of you will join the many members who are already in this special group. If you have any questions, please call Mary Ann Kibarian, PDSA Director of Development, at (877) 528-3538.

continued on the next page

President's Challenge

continued from page 14

If you are unable to make an annual $1,000 contribution but can organize a fund-raiser that will bring in at least $1,000 to benefit PDSA, we welcome you to join the President's Circle by meeting the challenge through fund raising.

Members Lauren and Brian Worsham organized a bull roast that netted more than $16,000 for the PDSA. Others who have become members of the President's Circle by hosting a fund-raiser include Therese Dotson (Halloween Raffle), Misty and Ken Carter (Josh's Ride), and Arlene Laut (Sarah's Walk).

Your fund-raiser can be any activity that nets at least $1,000 over the course of a year for the PDSA. Use your imagination and do whatever is interesting and fun for you. Want to try, but can't think of anything? Give us a call, and we can help you with some suggestions.

What Our Friends Are Saying

continued from page 14

The seminar didn't fully remove the mystery that is ITP (as it is still a mystery at the research level), but I just want you all to know I was very moved by what you all did. Thank you so very much. Please, please extend thanks from my wife and I to all who worked hard to arrange it and to the doctors and the med companies that helped with the grants and stuff. I am very thankful to you, Joan, for doing what you do. It was an honor to meet you briefly after the event. (Sorry we had our Disney uniforms on. We came straight from work!)

Thank you one and all,
Arnold and Martha

Dear Madam Joan Young,

May peace be upon you.

I am touched by your explanation and wish to help us. I've read some of the information on platelet disorders through your Web site, and it relieves me and my family so much. My son, Adam, is under our fullest supervision, and hopefully we could help him to go through this situation.

I hope all of us in Malaysia would be able to learn many things from PDSA and information on the Web site.

My appreciation is extended to you and all members in the PDSA, and we hope to have close ties in the future.

Thank you,
Shafini

Dear Joan,

Thank you for the information on the Name Exchange Program and your recent newsletter. I will consider it. I am also very interested in the conference to be held in Meadowland, N.J.

Last October, I attended the Stamford, Conn., Regional Seminar and learned a lot. Coming back, I started the macrobiotic diet. I lost 8 to 9 pounds in less than 4 months and feel very well. I just want to thank you and your team again for your kind heart in organizing PDSA. I am sure all the members appreciate your hard work and contribution.

Regards,
Ed

PDSA welcomes your letters and thanks you for taking the time to write. We love to hear from you. Send your letters to What Our Friends Are Saying, PDSA, P.O. Box 61533, Potomac, MD 20859, or via e-mail to pdsa@pdsa.org. *Letters may be edited for length and clarity.*

PDSA Bequest Society

If you have included PDSA in your will, please let us know so we can add you to this list of special donors.

PDSA Outreach

Updates on Local Support Groups

Local support groups provide a forum for members to exchange information and learn about new treatments, emphasizing all methods to promote wellness. The local groups support PDSA in many ways: They provide a forum to extend support on a personal basis to ITP patients, raise awareness of PDSA among physicians by taking packets of our publications to their doctors, and organize fund-raisers. Perhaps the most important role for local groups is the opportunity they provide to ITP patients and families to share their experiences.

There is nothing more comforting than speaking with someone who understands your illness. PDSA says "thank you" to the facilitators who are providing this wonderful assistance and encouragement for our membership.

CHATTANOOGA, TENN.

Facilitator: Sharon Putnam, *pdsa.chatt@windstream.net* or (706) 673-9877
Meeting dates: First group meeting was held Saturday, March 31.
Meeting location: Please contact Sharon Putnam for the next meeting location.

CLEVELAND, OHIO

What's new: This group has grown to 38 members!
Facilitators: Barbara Hise, *rehise@ameritech.net,* and Caroline Kruse, *kencaroline@ cox.net*
Meeting dates: Second Thursday of every month, 7 p.m. to 8:30 p.m.
Meeting location: Independence Cleveland Clinic, 5001 Rockside Road, Independence, Ohio, Conference Room B (on lower level). There is no charge for parking.

Twenty-six members of the Omaha, Neb., local support group came out to enjoy pizza, swap stories and have fun at the Amazing Pizza Machine on a recent Friday night. The group includes five children with ITP, who enjoyed meeting one another, and their families had a wonderful time networking. From left are Ethan Vonnahme, John Goding, Hannah Sederburg, Alec McCarthy and Zach Green. The group is planning a fund-raiser at the restaurant on May 1.

OMAHA, NEB.

What's new: A fund-raising event is planned for May 1 at Amazing Pizza Machine, 139th and S. Plaza in Omaha. PDSA will receive 10 percent of the total buffet sales! This is a "Terrific Tuesday," and with every buffet purchase, you receive free unlimited rides and video games. So come out and join us for this fun event!
Facilitator: Heidi Green, *bgreen6833@cox.net* or (402) 498-3826
Meeting dates: A family picnic and swimming event is planned for July.
Meeting location: Contact Heidi Green for specific meeting locations and dates.

SEATTLE, WASH.

What's new: Dr. Terry Gernsheimer, a medical adviser to PDSA and leading expert on ITP spoke at our meeting on April 1.
Facilitator: Cathy Hendrickson, *cah@stokeslaw.com* or (206) 764-7128
Meeting dates: June 3, Aug. 5, Oct. 7, Dec. 2 (all Sundays)
Meeting location: Overlake Hospital, Medical Office *(continued on page 18)*

Local Support Groups Newly Starting

There are five new support groups forming! If you are interested in joining, and/or helping, please contact the local volunteer facilitator listed below. They will be delighted to hear from you.

ATLANTA, GA

Virgina Holland-Davis: (770) 736-3417 or *atl_pdsa@yahoo.com*

CENTRAL NEW JERSEY

Susan Stromholm Anderson: (908) 526-0946 or *sstromholm@aol.com*

DALLAS, TEXAS

Linda Dorasami: *krld@flash.net*

STAMFORD, CONN. (2)

Marie Rossi: *msr47710@sbcglobal.net* and John Catalano: *jc930@optonline.net*

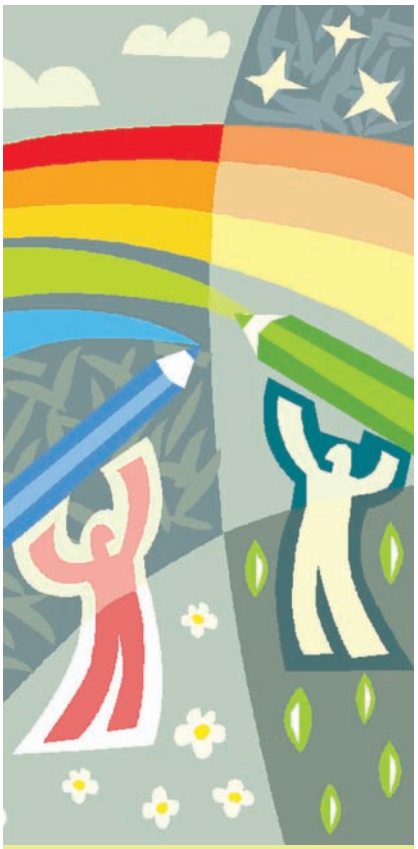
SWEETWATER, TENN.

Christy Miu: *dreamydate30@yahoo.com*

Would you like a support group in your area? **Are you willing to be a facilitator?** If so, contact Mary Ann Kibarian at *makibarian@pdsa.org* or call (877) 528-3538 for more information.

SAVE THE DATE

A Facilitator's Workshop will be offered at this year's Annual Conference, June 15-17, in Secaucus, N.J. The workshop, conducted by Caroline Kruse, longtime facilitator of the Cleveland group, will offer pointers to current local support group facilitators on how to have more successful sessions. Also, anyone interested in becoming a facilitator is invited to attend the workshop to learn the easy steps for starting a local support group and to pick up a manual. Details on the workshop will be in the Conference bulletin.



"I was going through your medical records from when you had purpura at the age of 7 … and I also noticed that you had had your MMR booster shot two weeks prior to being admitted to Children's Hospital."

Rainbow Page

ITP and the MMR Vaccination

Laura

I am a 40-year-old woman with ITP, presently in remission ... knock on wood. My story begins in 1973 when I was 7 years old.

One day out playing in the yard, I showed my mum that I had "purple dots" on my arms and legs. After a thorough body check, we discovered I had many unexplained bruises and "purple dots" (petechiae) on most of my body. My parents rushed me to the doctor, where the doctor was puzzled, and he had blood taken. After discovering my platelets were dangerously low, I was rushed to Children's Hospital in Boston and was thought to have leukemia. After many tests, I was told I had purpura and was hospitalized for a week until my platelets went back to a satisfactory level. The doctors never determined a cause.

Fast forward to 2001. I am married and have a daughter who is just over a year old. One night as I am brushing my teeth, I see that my gums will not stop bleeding; I have many unexplained bruises on my legs, inner thighs (huge ones) and an extremely heavy period. After seeing the horrid bruises, I call my doctor and am told to go to the emergency room, as I am "hemorrhaging." At the emergency room, my blood work came back, and my platelets were well below 10,000. I was told that they were going to run a leukemia test—the worst thing I could ever imagine and the worst results to wait for with a 1-year-old daughter at home!

Thankfully, I did not have leukemia, but I was then diagnosed (again) with ITP. I told the doctors that this had happened once before many years ago as a child. They could not determine the cause. They sent me home with Prednisone (120 mgs) and assigned me to the hematologist/oncologist on duty, who was wonderful! I went several times a week for blood tests and to be closely monitored. The Prednisone made me feel completely awful, as most of you know! I was washing the kitchen floor at 2 a.m., could never sleep and had a child who would wake up just as I finally drifted off to sleep.

For several months, my hematologist lowered the doses of Prednisone, dropping from 120mg to 100 to 80 to 40. But every time he'd try to take me off, my platelets would drop, and there would be more bleeding gums, petechiae and bruising. Finally he informed me that the "last ditch effort" would be to remove my spleen. After six months of the Prednisone, I had my spleen taken out, and it seemed to be successful.

Still, my doctor—and others in his office—deemed me "a science experiment" because they could never figure out the cause of my ITP reactions. My mother, who keeps every single thing from my childhood, one day said, "I was going through your medical records from when you had purpura at the age of 7 … and I also noticed that you had had your MMR booster shot two weeks prior to being admitted to Children's Hospital. I also realized that you had the ITP reaction as an adult two weeks after Kealani (my daughter) had her MMR shot. You should mention this to your doctor." Slightly embarrassed at having to tell my doctor what "my mother said," I did so anyway, and he found it extremely interesting. After we all searched the Internet, medical books, etc., we found that 1 in 45,000 *(continued on the next page)*

ITP and the MMR Vaccination

continued from page 17

(that was the last I checked) could have this type of reaction after the MMR shot. The two weeks is the prime time, as the measles part of that shot is live, and is live between approximately days 5 and 15. My doctor was stunned by this realization and said he has since seen a few other patients with ITP and has asked when their child or grandchild had their MMR or booster shot and the timing seems to be consistent. I now steer clear of any children around the age of 15 months (as that is usually when the first MMR shot is given), and any child ready to enter kindergarten, as they need their booster shot. It was rather tricky when I was at my daughter's preschool, as I could not ask each 4-year-old for their immunization chart while assisting in the class.

I do not touch children around that age; I ask parents of friends when their children have had their MMR; and I am basically "on my guard." When my daughter entered kindergarten, I discussed my situation with her doctor, saying I didn't want to have to leave my daughter for two weeks because she needs a booster shot. The doctor told me something very, very surprising! Most children are already immune after their initial MMR shot (95 percent, according to the doctor). We ran a simple blood test to determine whether my daughter already was immune, and she was! Why do they continue to administer these booster shots if most children already are immune?

Anyway, here I am, five years after my splenectomy, and I have not had a relapse. I have gone from weekly visits to my hematologist, to monthly visits, then every three months, every four months, every six months, and now, unbelievably, at my last visit, I heard him say: "See you in a year!"

I hope this may help somebody else—another child or maybe other parents scratching their heads two weeks after their children receive an MMR shot. Or maybe my story is a piece to someone's puzzle that they could never figure out.

PDSA Outreach

continued from page 16

Tower Building, conference room in the Cancer Resource Center. Please contact Cathy Hendrickson to RSVP or for more information.

WASHINGTON, D.C.

What's new: The Sept. 12 meeting featured a presentation on stress management and the latest information on ITP treatments for children. On Nov. 14, a Reiki practitioner explained how this method can be helpful to ITP patients. The February meeting was unfortunately "snowed out."

Facilitators: Sonia Vandama, *svandama@aol.com,* and Annette Greene, *annettergreene@yahoo.com*

Meeting dates: Second Tuesday of every other month, 7 p.m. to 8:45 p.m; upcoming meetings are April 10 and June 12. The topic for the April meeting will be "Alternative Treatments." For further information about the meetings, contact Sonia Vandama, or Annette Greene.

Meeting location: Georgetown University Hospital Center, Lombardi Cancer Center in the Martin Marietta Conference Room.

In Appreciation

We received the following donations and pledges of $50 or more from Oct.1, 2006, through Dec. 31, 2006. We appreciate and value your generosity. These contributions help make our programs possible.

PRESIDENT'S CIRCLE ($1,000 +)

Diane and Robert Joseph
Lavonne Webb

BENEFACTORS ($500—$999)

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continued on the next page

Fund Raiser: Bowl for ITP

More than 200 bowlers took to the lanes in Timonium, Md., on a recent Sunday, making the first Bowl for ITP a success and raising $1,800 to support PDSA. A local league joined some of our members in the fun at the AMF Timonium Lanes on Feb. 11, and, as an added attraction, there was a special visit by members of Extreme Champion Wrestling.

The general manager of the Timonium Lanes, Mary, had the full support of her employees: They all donated their salary for the day to the cause! All in all, it was a fun day for young and old. Mary was happy to organize the event because she has a special appreciation for the PDSA.

About 20 years ago, Chris Faith, of Baltimore, was diagnosed with ITP. He was just 15 months old. Chris is now a strapping 21-year-old. He survived all the trials and tribulations of those early years of endless transfusions because of the untiring love and attention from his mother, Mary Faith.

Mary, then a single mom, worked two or three jobs to get the money to pay for Chris' treatments. Insurance, as we know, does not cover experimental drugs, and in those years, many of the treatments were still new. Even the ones that were covered, IVIg and WinRho, were extremely costly. But through all the hard times, Mary persevered.

When PDSA came into being, Mary was grateful for Joan Young's supportive counsel and, most of all, *the information*. "Raising a teenager," said Mary, "is hard enough, but when he has a rare blood disorder and with information being so skimpy, it makes it even more tough. Joan was so helpful to me at that time. I want to show our gratitude by organizing this event for PDSA. I hope the success of this event will inspire more interest for Bowl for ITP to become a national event."

Mary also noted that the rarity of the illness didn't give patients many opportunities to meet other ITP patients, let alone participate in a safe, fun sport. This event accomplished that!

Chris still has ITP, but he has a terrific can-do attitude. He had a hard time when he decided he wanted a career in the Army. He applied to the Army and was accepted, but after his platelets dropped, he was sent home. He had the same experience with a local police department. But Chris now is happily working for the Comcast Cable Company in Maryland. We all wish him and Mary the best of luck and thank them for their support for PDSA.

A Different View

Unusual Success Stories From Our Mailbox

THESE LETTERS ARE FOR YOUR INFORMATION ONLY. FOR ADVICE ON YOUR UNIQUE MEDICAL CONDITION, PLEASE CONSULT A HEALTH CARE PROFESSIONAL.

My 21-year-old son was diagnosed with ITP more than two years ago. His platelet count was below 5,000. He was hospitalized and hooked up to an IV with steroids for a couple of days. His platelets went up to 75,000, but eventually dropped. He went online and spoke with other people and came to the conclusion (that he should) take a mass dose of vitamin C and potassium for a few months and lowered the dose after. His platelets have been at 150,000 ever since. He had his adenoids out when he was 4 and was never ever sick since. Not even a cold. (I'm wondering if that had anything to do with this.)

Thanks,
Ginger
A very relieved loving mother
cesarz10@comcast.net

Hi,

I wanted to thank you for publicizing Get Well Natural. I have been using their herbal remedies for less than two months and have seen some improvement in my platelet levels. Fingers crossed it will continue.

Thank you,
Jess
jecopperman@gmail.com

Dear Joan,

I had a bout of ITP in 1999 following a severe flu, which required platelet infusions and steroids. After that, I found Moducare Sterinol and have never had a recurrence—platelets have remained normal, except for one dip in 2006 to 100,000, and then back up again.

Regards,
Phil
philbarton@worldnet.att.net

Hi Joan Young,

I am Doris from Malaysia. I read your Web site and understand your health condition. I am an ITP parent of Britney, who is now 6 years old. I found her to have ITP when she was 4. Now her platelets are 24; before it was 12 (three months back) or lower. I send you this e-mail to share with you what I found to be a good supplement for her and what her current condition is.

At first, I spent a lot of money on various treatments, including IVIg and Blood Well. But those don't work for her, so now I am using a supplement called Beta Glucan. After two months, I brought my daughter for a checkup, and her platelets kept increasing. The doctor told me to keep monitoring her, and she will get well if her platelets keep increasing after six months.

It would be good if you can share this information with your ITP parents because it may help them. I will send you more product information if you want.

Have a nice day. Thank you.

Yours faithfully,
Doris
doris_chng@myjaring.net

(continued on the next page)

In Appreciation

continued from page 19

FRIENDS continued

Ioan Dumitriu • Nader Ebrahimi • Todd Endres • Richard Falsey • Brad Feltz • Aime Flores • Michele Follonier • Angela Fox • LeRoy Fox • Stuart French • Lanie Gastman • Lisa Gibson • Lana Goldberg • Charlotte Goldfarb • Ellen and Bruce Gordon • Sunny Greenberg • Annette Greene • Jennifer Grogan • Bridget Gruzdis • Annette Gudson • Ed Hadd • Michael Halpern • Leslie Harbold • Nancy Harrington • Charlie Harrington • Jamie Canfield Harwell • Istvan Hegedus • Joy Heinbaugh • Tammy Heidrich • Sarah Holst • Patricia Horeisch • Nancy and Michael Jenkinson • Gaby Jerles • Tom Joplin • The Kaplan Family • Hilde Kasper • Edward Klug • Irving Konigsberg • Christine Kroeger • Fay Kunz • Robert Labay • Steven Lam • Susan Lang • Ann Lanoux • Andrea Lattarulo • Joe Luzar • Lucille Marchione • Frances Martino • Kate Mattice • Thomas Morris • Kim Moser • Beverly Muddiman • John Nadeau • Ellis Neufeld • Sandra Noykoff • Filippo Occhino • Patricia Olson • Cathy Peitz • Rae Peterson • Ronald Pietz • Lisa Rice • Ilene Riethmeier • Klaus Roemer • Sallie Rogers • Karen Rosenbaum • Henry Rossett • Dennis Ryan • Wayne Salk • Rosanne Seitz • J.C. Shannon • Rebecca Shepard • Becky Singletary • William Smith • Mary Ann Steinbis • Diane, Erin, and Naima Stepheson • Max Strebel • Mary Paull Taylor • Jeanette Teesdale • Mireille Threlkel • Nancy Toubia • Joan Turo • Kimberly and Troy Upah • Linda Wagar • Irwin Wall • Cheryl and Ken Watsey • Elizabeth Weaver • Gregg Weinberg • Audrey White • Ann and Gordon Willett • Marcia Wireman • Phyllis Wisniowski • Joe Yurkanin • Helen Zingman

New Platelet Pal Art Contest

Calling all PDSA kids! The 2007 Platelet Pal Art Contest is under way. We are looking for drawings that depict the winter holiday season for this year's contest. What is your favorite scene or activity that represents the holiday season? Drawings can be done in any medium. Please send your submissions to PDSA no later than May 15, 2007. Winning drawings will be boxed and sold as holiday note cards. In addition, the winning drawings will be displayed at PDSA's Annual Conference in Secaucus, N.J., in June.

Send your drawings to Mary Ann Kibarian, PDSA, 133 Rollins Ave., Suite 5, Rockville, MD 20852 or e-mail *makibarian@pdsa.org*. Be sure to include the artist's name, age, address, parent's telephone number and e-mail on a separate sheet of paper or in the e-mail.

Kid's Korner

Note Cards to Support ITP Research

You still have an opportunity to purchase a box of the Platelet Pal Art Contest cards! Everyone is talking about these wonderful cards. You don't want to miss out on a charming gift for friends or for your own correspondence throughout the year.

The cards are all "originals" submitted by children ages 14 and younger. Each note card is approximately 4 inches by 6 inches with a child's artwork on the front. The name, age, state and country of the artist and the title of the work are on the back of the card.

Each box includes 14 different cards with envelopes and sells for $17.95, including shipping and handling. **All proceeds from the sale of these cards will be used to fund ITP research.**

You can purchase these delightful cards by contacting PDSA or by shopping online in our Platelet Store, *http://store.shoppdsa.org*

A Different View

continued from page 20

Hi Joan,

Since you published my letter last summer regarding Sara's story and how similar it was to Dr. Conley's protocol (I read about in the previous newsletter), I thought I'd update you on Sara's progress. Sara's letter came out right before her checkup in June. She actually dropped by 10,000 down to 93,000. What's a few thousand platelets between friends, I told her. In July, Sara went to get her food sensitivities updated, and Sara was thrilled she could eat corn products again! Although corn syrup is still a no-no, as well as gluten and dairy. Last week we again went to Children's Hospital for her six-month checkup, and her platelets went up to 128,000!!! Needless to say, we are thrilled. Hopefully when Sara returns in June, her count will be normal. By sharing Sara's story, hopefully it can give hope and insight to help others to take avenues they may not otherwise have thought of taking. As I stated in Sara's story, I don't think the solution will be the same for everyone. I do believe that finding out what is out of whack in your body and then doing what you can to return balance will allow the body to heal and allow the body to do what it needs to do to in order to return the platelets to normal or much closer to normal.

Good health to all,
Diana
Mother of ITP Child
pickupfam@aol.com

If you have an unusual success story to share, we'd like to hear it. Send your letters to A Different View, PDSA, P.O. Box 61533, Potomac, MD 20859, or via e-mail to pdsa@pdsa.org. *Letters may be edited for length and clarity.*

ITP Conference 2007

UPDATE ON IMMUNE THROMBOCYTOPENIC PURPURA FOR PATIENTS, CAREGIVERS, AND PHYSICIANS

June 15-17 • Crowne Plaza Hotel Secaucus-Meadowlands • Secaucus, N.J.

Registration is now open for what will be our best conference ever. This year we will have more speakers and more opportunities to meet each other than ever before. In addition to a stellar lineup of speakers, we have added optional events: yoga in the morning, a Saturday evening dinner and party, and energy healing sessions.

We have more information on our Web site and in the conference booklet that we will be sending soon.

I look forward to seeing everyone in June.

We thank GlaxoSmithKline for their Platinum level support of our ITP Conference.

GlaxoSmithKline

The conference will be in Secaucus, N.J., near New York City, with easy access from Newark airport. You can extend your stay to shop at the nearby outlets, go to events at the Meadowlands Sports Complex, or take a 15-minute train ride to Manhattan.

United Way and Combined Federal Campaign Contributions

We received donations and pledges (Oct. 1, 2006, through Dec. 31, 2006) from the following individuals from their local United Way and Combined Federal Campaign Agencies.

MEMBER/CONTRIBUTOR AND LOCAL CAMPAIGN UNITED WAY

Anonymous, *Metropolitan Atlanta, Ga.*
Janet Doyle, *United Way*
Ami Flores, *AT&T Campaign—United Way*
Valerie Gregory, *United Way*
Sandra Gutierrez, *AT&T Campaign—United Way*
Mindy Haring, *Western Montgomery County, Pottstown PA—United Way*
Linda Lalicata, *Greater Milwaukee United Way*
Patty and Dirk Leasure, *BMO*
Dean Lipperman, *Charity Choice*
Linda Lopez and Heather Esperanza, *AT&T Campaign—United Way*
Sherry Obrien, *AT&T Campaign—United Way*
Maria Palmores, *AT&T Campaign—United Way*
Kathy Reinert, *Western Montgomery County, Pottstown, PA—United Way*
Richard Ripple, *AT&T Campaign—United Way*
Jessica M. Smith, *AT&T Campaign—United Way*
Andrew Strada, *GE CPARS*
Lynda Wood, *Central Maryland United Way*

continued on the next page

United Way and Combined Federal Campaign Contributions

continued from page 22

CFC

Anonymous, *Baltimore, Md.*
Anonymous, *Eastern Massachusetts*
Anonymous, *Fort Polk—Central Louisiana*
Anonymous, *Kalamazoo, Mich.*
Anonymous, *Leavenworth, Kan.*
Anonymous, *Los Angeles, Calif.*
Anonymous, *Milwaukee, Wis.*
Anonymous, *New York, N.Y.*
Anonymous, *San Francisco, Calif.*
Anonymous, *SWPA*
Armida Bravo, *Puerto Rico*
Ann Lanoux, *New Orleans, La.*
Gerald Silberlight, *New York, N.Y.*

PDSA
PLATELET DISORDER SUPPORT ASSOCIATION

ITP CONFERENCE 2007 PATIENT AND CAREGIVER

Registration Form

Mail to: PDSA, P.O. Box 61533, Potomac, MD 20859
or fax, with credit card payment information to 301-770-6638

	MEMBER	NON-MEMBER
EARLY REGISTRATION: THROUGH MAY 7, 2007		
Individual	$110.00	$130.00
Family (2)*	190.00	225.00
REGULAR REGISTRATION: MAY 8 – MAY 31, 2007		
Individual	$140.00	$160.00
Family (2)*	240.00	265.00
LATE REGISTRATION: AFTER MAY 31, 2007		
Individual	$160.00	$180.00
Family (2)*	260.00	285.00

*If you would like to register more than two people in your family call us toll free at 1-877-528-3538.

Conference registration includes Friday evening reception, continental breakfast Saturday and Sunday, box lunch on Saturday, and Saturday night fun event.

_____ PDSA Member Registrations @ $ _____ $ _____

_____ Non-member Registrations @ $ _____ $ _____

_____ Saturday Night Dinner, $35 per person $ _____

_____ PDSA Membership ($25 or more) $ _____

❍ I would like to add an additional amount to defray conference expenses $ _____

Total $ _____

❍ **Check** or money order enclosed payable to PDSA. (U.S. funds only, no cash)

❍ **Charge** my: Visa ____ Master Card ____ American Express ____ Discover ____

Credit Card #: _____ Amount charged: $ _____

Expires: Month _____ Year _____ Signature ***(required)*** _____

ATTENDEE INFORMATION (PLEASE PRINT)

On a separate sheet of paper, please include name, address, & phone number ***for each attendee.***

Name: _____

Address: _____

City: _____ State (Prov): _____ Zip (Postal) Code: _____

Country: _____ E-mail: _____

Telephone (day): _____ (eve): _____

❍ I have special dietary needs (indicate): _____

OUR MISSION

The Platelet Disorder Support Association is dedicated to assisting patients with immune thrombocytopenic purpura and other platelet disorders through education, advocacy, and research

Thank you to Baxter Healthcare for supporting the publication of our newsletter.

Join Us

PDSA IS A 501(C)3 NONPROFIT CORPORATION. ALL CONTRIBUTIONS ARE TAX-DEDUCTIBLE.

___Member ($25+) ___Friend ($50+)

___Contributor ($100+) ___Associate ($250+)

Amount: _____

(checks in U.S. funds payable to PDSA)

Charge my: ___Visa ___MC ___AmEx ___Discover

Expires: Mo. _____ Yr. _____

Card Number _____

Signature *(required for credit card orders):* _____

Name _____

Address _____

City, State, ZIP _____

E-mail _____

Phone No. _____

PDSA
PLATELET DISORDER SUPPORT ASSOCIATION

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