ASH 2011 Conference Special Edition

The Platelet News

VOL. 13; NO. 4 **WINTER 2012**

ITP Research Update: News from the American Society of Hematology Meeting

Part 1

By Joan Young

Each year, in early December, thousands of physicians, researchers, pharmaceutical representatives, publishers, and anyone else (including people from PDSA) interested in the latest happenings in hematology gather at the American Society of Hematology (ASH) meeting, this year held December 10 to 13 in San Diego, California. Attendees choose from many hours of scientific, educational, research and industry presentations. They attend special interest meetings, review the thousands of posters, and roam the vast exhibit area. Most leave tired, with achy feet from walking the distances between meetings, and sagging shoulders from carrying the gathered information. The effort is worth it, however, since the meeting always yields a treasure of information.

PDSA Board Chair, Peter Pruitt, and wife, Barbara Pruitt, assisted in PDSA's booth at the ASH conference in San Diego

Once again, PDSA had a booth at ASH where physicians and researchers from all over the world stopped by to pick up our booklets and articles. The three most popular items this year were our newest publications: *ITP and the Female*

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2012 Showcases

PDSA 12TH ITP CONFERENCE IN DENVER, CO

By Caroline Kruse

PDSA will present the 12th annual update on immune thrombocytopenia (ITP) for patients, caregivers, and the medical community July 20 – 22, 2012 at The Inverness Hotel and Conference Center, in Englewood, Colorado, just outside Denver. Offering spectacular Rocky Mountain vistas under expansive Colorado skies, The Inverness presents an ideal destination for fun and relaxation — all

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In This Issue

IMPORTANT: The information contained in this newsletter is for educational purposes only. For advice on your unique medical condition please consult a health care professional.

PDSA
PLATELET DISORDER
SUPPORT ASSOCIATION
for People with ITP

From the Executive Director

"Why did this happen to me?" It's the one question anyone diagnosed with a chronic disease wants answered. Over the years, I had my many theories on what caused my ITP. I started feeling the extreme fatigue that often accompanies ITP about six months after the birth of my second child — was it something about the birth or the fluctuating hormones? My family moved into a new home around that same time — was it something about the house, the neighborhood? I had worked at a TV station that was built on a landfill and for years there were rumors that employees of the station had a higher than normal rate of cancers and other rare illnesses — was I one of them? Even my 90-year-old grandmother had her hunch — it was the funny lettuce that I was eating. (Grandma only ate iceberg lettuce and did not believe in the nutritional value of red leaf or romaine!)

Since my initial diagnosis 12 years ago, I resigned myself to the fact that I would never know what caused my ITP. So imagine my shock when recent blood tests revealed I have Hypogammaglobulinemia or Common Variable Immune Disorder (CVID). I've been told by the experts that more than likely it is related to my ITP and that it is probably more common among ITP patients than we know. Because I have never had any major infections or illnesses over the years, my hematologist did not suspect that CVID was the cause of my ITP, nor did he test for it.

Of course, this has created a whole host of new questions in my mind. The reporter in me will continue to investigate to see how this diagnosis will not only impact my life, but what implications it might have for my fellow ITP patients. Stay tuned…

To learn more about CVID, visit our newly updated Other Platelet Disorders Web page at http://www.pdsa.org/resources/other-platelet-disorders.html

Caroline

Caroline Kruse, Executive Director
Platelet Disorder Support Association

Join The Circle of Hope!

Your valuable donation will enable PDSA to enhance the programs and services that help those suffering with ITP and other platelet disorders.
For more information about making a gift of $1,000 or more, contact Caroline Kruse, Executive Director, at (877) 528-3538 toll free or by e-mail, *ckruse@pdsa.org.*

Membership Donation Makes a Difference

Is there someone you know who could benefit by receiving our quarterly newsletter, *The Platelet News?*

You can make a difference in the life of someone touched by ITP just by donating a membership to PDSA. And you'll be supporting an organization that has for more than 10 years been the lifeline for those with ITP and other platelet disorders.

Just go to the PDSA Web site *(www.pdsa.org)* and click on the "Membership" tab for details. You may also contact our office toll-free at 877-528-3538.

New Year – New Look!

In 2011 we expanded *The Platelet News* from 24 to 28 pages due to the increase in information — from research to advocacy from support group news to patient letters from fundraising to our walk/run events from awareness activities to Sport Purple for Platelets day!

With all this activity, we decided it was time for a new and fresh look for *The Platelet News.* Please know that we continue to be cost-conscious, so the printing costs have not increased because of this new look. We hope you like the new layout, combination of colors and glossy paper. We welcome your feedback!

p.s. The monthly e-newsletter has a new look too!

Now available by popular demand…

ITP Awareness Ribbon Car Magnets

Help spread awareness of ITP and PDSA

$6.00 each (1 – 4 magnets)

Dimensions: 4.2" x 6.8"

ITP Awareness Ribbon Car Magnet 5-Pack: $25.00

VISIT THE PDSA WEB SITE TO ORDER:
www.pdsa.org

The Platelet News

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SUPPORT ASSOCIATION
for People with ITP

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All contributions are tax deductible.

News from the American Society of Hematology Meeting

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Lifecycle, and our two French translation booklets: *ITP in Adults and ITP in Children.*

Although ITP and other platelet disorders are only a small part of ASH, there is plenty of information to fill several newsletter articles. This first article will focus on the research abstracts and related oral presentations. Future articles will cover the other sessions. We are pleased to share what we gathered with you.

PDSA' s Medical Advisory Board members joined PDSA Board Chair, Peter Pruitt, and PDSA Executive Director, Caroline Kruse, for a luncheon at this year' s ASH Meeting in San Diego, CA (Pictured, 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)

Below are one sentence research trends, a very abridged view of the abstract information. Details follow.

- ITP research is increasingly global.
- The use and understanding of TPO agents are growing.
- Companies continue to search for new treatments for ITP.
- There is less emphasis on the benefits of splenectomy and more on predicting success.
- Current treatments continue to be analyzed singly, in combination, and in comparison with each other.
- Researchers are using genetics and other markers to help determine which treatments have a better chance of working.
- The impact of ITP on quality of life continues to be studied and appreciated.
- You have to look really hard to find any studies mentioning complementary or alternative treatments.
- More is discovered about the genetic causes of low platelets.
- There is slow and steady progress in understanding the intricacies of ITP and platelets.

(The abstract numbers, where available, are listed in parentheses. You can read the full text of the meeting abstracts at: *http://ash.confex.com/ash/2011/webprogram/start.html*. Click on 'agree')

ITP research is increasingly global

Despite the "American" name, the meeting has always drawn a large contingent from outside of the United States. The international collaboration solidified a few years ago with committees of researchers from many countries meeting to finalize the International Consensus Report on ITP and discuss the standardization of terms and research criteria. The global cooperation continues unabated. Of the 50 research abstracts of interest to our readers, 31 originated outside of the US. At the ITP breakfast on Friday morning, six of the 10 presentations were done by non-USA researchers.

The use and understanding of TPO agents are growing

Eltrombopag (Promacta®/GlaxoSmithKline) and romiplostim (Nplate®/Amgen), thrombopoietin (TPO) agents that stimulate the bone marrow to produce more platelets, have now been used to treat ITP for several

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PDSA Welcomes two new Board Members, Brian Bamesberger and Jay Charness

By John Boyle

Just as we welcome 2012, so must we bid farewell to two long-serving members of PDSA's Board of Directors: **Dirk Leasure** and **Susan Anderson**. Dirk, who joined the Board in 2005, and Susan, who joined the Board in 2006, both finished their terms in December. Though both are rotating off of the Board, both remain great friends of PDSA and the ITP community. For their years of commitment, energy, and leadership, we thank them both for their roles in advancing PDSA's mission.

While filling their shoes won't be easy, Dirk and Susan's successors both come to the PDSA Board with significant passion for the ITP community.

Brian Bamesberger

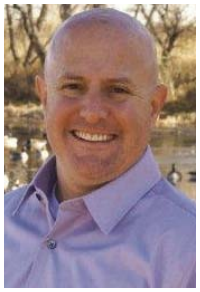
Many readers of *The Platelet News* know Brian from last fall's phenomenally successful Peak Performance fundraiser. Along with trainer Lance Darling and a small army of friends and community members, the Bamesberger family helped raise over $80,000 for PDSA in 2011.

The reason for Brian and his wife Kenda's commitment to the ITP community is their teenage son, Jacob. Diagnosed when he was almost four years old, Jacob's years of dealing with ITP have brought the entire Bamesberger family close to PDSA. From their attendance at the San Francisco ITP Conference nearly a decade ago, Brian says that his family "couldn't have done it without PDSA" as his family was learning about ITP and adjusting to Jacob's diagnosis.

In his new role as a Board member, Brian is eager to start his term by getting to know his fellow Board members, learning, and lending a hand as a "worker-bee."

Brian is the president of Star Companies. He and his family reside in Loch Lloyd, Missouri.

Jay Charness



Jay is well-known to many ITP parents as the voice and the driving force behind the PDSA parents teleconference support group. He and his wife Audrey have been involved with PDSA since their daughter, Ayla, was diagnosed with ITP when she was 3 ½.

Over the last seven years, Jay has reciprocated the information and support that his family received in their early days with PDSA by becoming a valuable resource for parents of ITP children. His family's story helps deliver a powerful message about parents empowering their children to play an active role in their care.

As Jay transitions into his new role as a Board member, he looks forward to helping PDSA increase awareness about ITP, and helping to promote participation of the ITP community through PDSA membership.

Jay is the owner of ProLine Machinery, the author of *Get It!*, and is the founder and executive director of "A.P.E.," a non-profit organization that works with children and adults on safety, self-awareness, and self-defense. He and his family reside in Arvada, Colorado.

PDSA has a *NEW* Facebook Page

If you LOVE PDSA, then be sure to 'Like' our NEW FACEBOOK page.

Like us on Facebook

PDSA has already been on Facebook through our causes page. Now through our NEW Facebook page PDSA has established another way to reach out to those who are coping with or affected by ITP. This provides a direct online forum for comments and sharing news and information about ITP, treatments, and the ups and downs of this platelet disorder.

Check out our page at *http://www.facebook.com/plateletdisorder* and let us know you 'like' us!

Here are some comments we've received on our NEW Facebook page:

"PDSA has kept me informed about the latest meds and I knew about them before my hematologists. As a result, I am doing very well on Promacta® (eltrombopag). I am deeply grateful for PDSA." – Rae P.

"This group has given us the BEST support! Amazing amounts of information that has helped us more than the Drs! We love PDSA! Platelets up!!" – Brandy D.

"The PDSA Web site and conferences were such a big part of my journey with ITP that I want to give back to PDSA so that others will continue to have the benefits that it provides. The articles, message boards, and newsletters always gave me new things to think about and discuss with my doctor. The first conference that I went to was the first time I didn't feel alone in having ITP. That is why I donate money to PDSA." – Megan R.

Introducing

The Circle of HOPE

By John Boyle

Longtime readers of *The Platelet News* have seen the creation and evolution of PDSA's two donor recognition groups: the President's Circle and the Executive Director's Challenge. The former was created to recognize individuals who gave $1,000 or more in a year, while the latter was used to recognize individuals who raised $1,000 or more in a year.

But to quote Bob Dylan, "the times they are a-changin'." Over the last couple of months, we've been replacing those names with a single name: the **Circle of Hope**.

At one level, the Circle of Hope is a merger of the two previous groups. From this point on, if an individual donates, directs, or raises $1,000 or more in one calendar year, they will be recognized as a Circle of Hope member.

To us, though, this is more than a re-naming or re-branding. It is a reflection of our increasing number of leadership donors that are supporting PDSA, and the multitude of ways in which they make those gifts.

While we are grateful for all of our members and supporters, Circle of Hope members play an especially important role in the life of our organization. PDSA receives very generous grants from corporations and organizations, but those grants are usually for specific initiatives. As a result, we rely on our members — especially our leadership donors — to give us greatly-needed flexibility in fulfilling parts of our mission that are not covered by grants.

To thank our Circle of Hope members, we provide all of our traditional member benefits, free registration to the ITP Conference, and a growing number of additional recognition opportunities that you can read about at *www.pdsa.org/hope*.

To become a Circle of Hope member, there are three primary avenues:

The first way is by making cumulative charitable gifts of $1,000 or more in a single calendar year (1/1 to 12/31). This can be through a single gift, or through a combination of gifts including fundraiser registrations and payroll deduction gifts. Please note, though, that Platelet Store orders and matching gifts made by an employer do not count toward your cumulative giving total.

The second way is by directing a gift of $1,000 or more from a family foundation where you are a trustee, a company you own, or a similar entity. On a related note, gifts from some private foundations are also eligible for membership.

The third way is by organizing a fundraising event where the net amount donated to PDSA is $1,000 or more. If you are interested in helping PDSA significantly advance its mission by becoming a Circle of Hope member, please contact John Boyle at (877) 528-3538 or *jboyle@pdsa.org*.

Making a Difference

Barbara Pruitt

By Carol Hoxie

IN HONOR OF PDSA FOUNDER JOAN YOUNG, THIS REGULAR FEATURE WILL HIGHLIGHT INDIVIDUALS OR A FAMILY WHOSE EXPERIENCE WITH ITP HAS LED THEM ON A REMARKABLE PATH TO MAKE A POSITIVE IMPACT IN THE LIVES OF OTHERS. WE HOPE YOU WILL FIND STRENGTH AND HOPE IN THEIR INSPIRATIONAL AND REVEALING STORIES.

For more than 50 years, Barbara Pruitt has lived with a platelet count less than 10,000. But she has never let her ITP stop her from living a full and inspiring life filled with family, children, friends, work and travel. Her optimism and hopeful attitude have been a comfort to so many with ITP who have heard her speak or shared a private conversation. And despite the fact that none of the ITP treatments helped raise Barbara's platelet count, she never stopped searching for answers for herself and for others affected by this disease.

Barbara Pruitt developed ITP in childhood, at age 4. Back then she was given steroids, but not like today's prednisone. Instead, "It was cortisone, ugly, bitter-tasting pills," Barbara said. However, the steroids didn't help that much, so at age 7 she had her spleen removed. Those were the only options back in the 1960s. At first she went into a remission. Then, after three months, she was given the oral (white liquid) polio vaccine (which contained live virus), and relapsed. She has been dealing with ITP ever since.

She spent her childhood in Florida, growing up in the Miami area. Although she did have to be careful with her low counts, Barbara didn't let her ITP hold her back. She went to Lindsey Hopkins School of Nursing, in Miami, and graduated with her L.P.N. degree in nursing. Although initially she was interested in being an artist, Barbara said she was drawn to the medical field because of her ITP experience. Barbara worked in nursing for 10 years in the Intermediate ICU at Baptist Hospital in Miami and eight years in a Cardiology practice. She married her husband Peter Pruitt, who has been her greatest supporter. They have two adult children, Ashley and Pete. She says Peter is her 'watchdog'. He looks out after her and reminds her what she shouldn't be doing or eating.

After her medical career, Barbara had an interior decorating business in Miami for about 10 years. Barbara closed the business in 2000 as her kids were getting older and the business was very tiring. She found that having ITP and carrying on the business was wearing her out.

Barbara is now steroid resistant and the available medications and treatments have not been successful in raising her counts. She has also participated in numerous clinical trials, hoping to find some answers.

One night about 10 years ago, while surfing the Internet, she came across the PDSA Web site. Barbara said in 40 years of having ITP, she had never met anyone else who had ITP. As she read the threads on the PDSA site, she realized there were others who knew what she'd been going through. Barbara said it was an epiphany moment for her.

The next morning she called Joan Young, the founder of PDSA, to let her know she'd seen the Web site and to ask, "What can I do? How can I get involved?" Barbara has been involved with PDSA ever since that day. Barbara said the first time she ever met another ITP patient

(CONTINUED ON THE NEXT PAGE)

Barbara Pruitt, in January 2012, showing her ITP bruise

> "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

Making A Difference

CONTINUED FROM PAGE 6

was at PDSA's annual ITP conference, held that year in Baltimore. There she met an 11-year-old boy with ITP in the elevator on the way to the conference and they struck up a conversation.

Barbara said, "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! As much as your husband, family, and friends love you, they really have no idea what it's like to have ITP!"

Barbara has been fortunate to have excellent medical care. In the 1970s she started seeing Dr. William Harrington at the Center for Blood Diseases at the University of Miami. Dr. Harrington was the 'guinea pig' doctor that made the landmark discovery about ITP being an autoimmune disease. She continues to see Dr. Yeon Ahn today.

In her search, Barbara has also tried natural and complementary treatments to help her platelets. Most recently, she was evaluated for food and chemical sensitivities using a blood test called the ALCAT. It tests for sensitivities, rather than allergies. Many sensitivities were found. When Barbara stopped eating those foods, she lost over 20 lbs, found her fatigue lifted and she felt much better, although she said her platelet count didn't rise.

She has been involved with PDSA in many ways over the past nine years. In addition to attending the annual conferences, Barbara has been a volunteer guest speaker on patient panels to share her ITP experience. For example, at the 2009 conference, Barbara described the ways she had learned to cope with a low platelet count. She hasn't let her low counts keep her from traveling. She told the audience that when she flies, she avoids taking an aisle seat where she is more likely to be bumped and bruised by passing carts, luggage, and passengers. In restaurants, she takes the seat nearest the wall, so she won't be near the aisle and bumped by other diners and servers. She carries a zip-lock bag with her in case she needs a quick ice pack.

In 2007, Barbara was filmed and featured as one of the ITP patients in the PDSA DVD 'Letting in the Light'. The DVDs have been distributed to hundreds of ITP patients each year, helping to spread Barbara's ITP story and words of encouragement and hope for others with this baffling disorder. In 2009, Barbara, along with PDSA Executive Director Caroline Kruse and Medical Advisor Jim Bussel, were featured in the PBS TV program 'Healthy Body, Healthy Mind' on the episode *ITP: The Hidden Blood Disorder.*

Barbara and her husband, Peter (PDSA's current Board Chair), have attended many annual ASH (American Society of Hematology) meetings in various US cities, where they helped out at the PDSA booth, handing out materials and greeting doctors and others attending these huge medical conferences.

It hasn't been easy for Barbara to attend these meetings where new information about diagnosis and treating ITP has been shared with the medical community and patients. She said with her ITP many times she has been tired and unable to attend the entire daylong meeting, requiring an afternoon nap to make it through the evening events. She often walked around with her visible bruises.

Barbara and Peter signed on as Charter Members of the PDSA Presidents Circle (now the Circle of Hope) in 2006 and have continued to support PDSA and those with ITP through their ongoing financial support. In 2007, Barbara served as the Board Chair for PDSA's Board of Directors. PDSA's current Executive Director, Caroline Kruse, was also a Board member at that time. "Barbara recruited me to serve on the PDSA Board of Directors. I still remember our first conversation. She is such a warm and smart person and you can't help but want to do more for ITP patients and PDSA once you meet Barbara. On a personal level, she has become a dear friend and I am continuously inspired by the way she lives her life with such passion, grace and courage," said Caroline.


PDSA Executive Director, Caroline Kruse with PDSA Board members, Barbara Pruitt and Diane Joseph at the 2008 ITP Conference

Many people with ITP have asked her how she lives with such a low platelet count from year to year. Barbara replies, "There's a lot of life to live. Letting the fear in on a daily basis is never a good thing." She said with ITP, "It's a lifelong relationship with your ITP doctor." Barbara said her nursing background really helps in her conversations with her doctor.

Barbara's original interest in art has resurfaced. In the past few years Barbara has taken up a new interest: jewelry-making and silver-smithing. She has been creating assorted necklaces, bracelets, and earrings that she sells. She has held many jewelry sales in Florida, North Carolina, and Maryland and donated all the proceeds to PDSA. For the past three years she created pieces that were raffled off at PDSA's

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Walk / Run News

Pump It Up for Platelets! Locations Continue to Grow, Spread Awareness and Raise Funds for PDSA and ITP

LOCATIONS FOR THE 2ND ANNUAL NATIONAL WALK/RUN HAVE MORE THAN DOUBLED, GENERATED SIGNIFICANT MEDIA COVERAGE, INCREASED DONATIONS, AND CONTINUE TO TOUCH THE LIVES OF THOSE WITH ITP.

By Nancy Potthast

Below are reports on more of the 2011 events. If you're inspired by what you read, remember — It's never too late to get in the game! Let's make 2012 an even greater success as we continue our mission to raise public awareness for ITP.

Arlington, WA – September 24th – Over $2,100

Astonished by the high cost of treatment for both her sister and aunt, high school student Ashlie Jensen felt compelled to raise awareness for ITP. With the help from family, friends, and community members, Ashlie organized a benefit walk that raised over $2,100 in support of those affected by the disease! Ashlie's efforts have helped PDSA help those with ITP. Fantastic job, Ashlie!

Burlington, CT – October 30th – Close to $700

Due to the record-breaking snowstorm that hit the Northeast the weekend of October 30, 2011, the Burlington event was postponed until the spring of this year. Despite the postponement, 16-year-old event organizer, Emily Guilmette, collected close to $700 before event day! Thanks to Emily, not only has she helped support PDSA programs and research, but she has also helped support other teens with ITP by sharing her personal journey with the disease. Way to go Emily!

Rockville Centre, NY – November 6th – Over $5,500

What began as a service project for 13-year-old NJHS member and ITP patient Stephanie Wettstein quickly became an outstanding community event that raised over $6,500 for PDSA programs and research! The efforts of Stephanie and her sister Lindsey (who has Gardner-Diamond Syndrome, which causes painful bruising) not only generated phone calls from local ITP patients, but also produced a local newspaper article about ITP as well! Special thanks to all who supported the efforts of these young and upcoming philanthropists. Great job!

North Babylon, NY – November 20th – Over $4,100

North Babylon organizer, Maryann Navarre gave new meaning to the word "friendship". When her dear friend, Michelle, was diagnosed with ITP in February 2011, she felt scared, confused, and her whole life changed. Determined to help raise awareness in support of her friend, Maryann quickly organized an amazing community event that raised over $4,100! The special touch of Maryann and the participants extended far beyond the North Babylon community — they've joined hands with volunteers in support of ITP patients around the globe! PDSA is forever grateful for the lives they have touched and their support of our mission.

A warm PDSA THANK YOU to all of our organizers, volunteers, sponsors, participants, and donors who continue to work together until ITP becomes as well-known as cancer.

Silver Sponsors

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In Appreciation

We received the following donations and pledges of $1,000 or more between October 1, 2011 and December 31, 2011. We appreciate and value your generosity. These contributions help make our programs possible.

CIRCLE OF HOPE ($1,000 +)

The following individuals qualified for Circle of Hope membership. Circle of Hope members donate or raise $1,000 or more within a calendar year and serve as our philanthropic leaders.

Anonymous (2)
Sara Armstrong
The Avrick Family
The Birny Mason Jr. Foundation
Audrey and Jay Charness
Allison Flowers
Terry Gernsheimer, MD
Robert Halonen
Michelle Ingargiola
Louise Kittel
Arlene Laut
Marjorie Ligelis
Warren Munash
Rae Ellen Pistone
Shirley and Peter Pruitt
Barbara and Mark Rice
Sharon and David Roberts
Jennifer Roberts
Carlos Sabater
Sheila and John Schwartzman
Michelle Wettstein
Stephanie Wettstein
Ray and Barbara Womack
Stephanie Zane
Cheri and Derek Zimmerman

In Memory

We received contributions between October 1, 2011 and December 31, 2011 in memory of:

Laura Christine Baldwin
Marie Dennis
Saurav Ghosh
Sandra Heyman
Paige Roberts

In Honor

We received contributions between October 1, 2011 and December 31, 2011 in honor of:

Emily Auterson
Kelly Brown
Jessica Cohen
Shelby Edwards
Bonnie Essex Hillegass
Angie Johnson
Dr. Mary Anne Knovich
Casey Krager
Alexandria Milidantri
Colin O'Dawe
The Pamplin Family
Bradley Salvador
Palmer White
Ron Paul's Granddaughter

If you would like to make a gift in honor or in memory of a friend or loved one, you can make your gift online at *pdsa@pdsa.org*, by mail, or by phone by contacting PDSA, 133 Rollins Avenue, Suite 5, Rockville, MD 20852 or calling (1-877-528-3538) toll-free. For more information, please contact John Boyle at (877) 528-3538 or *jboyle@pdsa.org.*

Highlights of 'ITP in Children: Q&A' Part 2

PRESENTED AT ITP CONFERENCE 2011 BY DRS. AMY GEDDIS AND MICHAEL TARANTINO

By Carol Hoxie

Pediatric hematologists Dr. Amy Geddis of Rady Children's Hospital in San Diego and Dr. Michael Tarantino of the Bleeding & Clotting Disorders Institute in Peoria, IL, met with a roomful of parents of children with ITP and answered many questions. Part 1 of the Q&A from the ITP Conference was printed in the fall 2011 issue.

Treating ITP with 6-MP

Q: What about treating ITP with 6-MP?

A: DR. TARANTINO: 6-MP is mercaptopurine (trade name Purinethol®), an anti-cancer drug used to treat leukemia. It has been around for a long time, is an immune suppressive drug, and has also been used for autoimmune diseases. It has scattered experience in treating people with ITP. It is, I think, an effective medicine as a second line medicine or a subsequent therapy when frontline therapies don't work.

Every immune suppressive medicine does have its risks and 6-MP does, in some cases, cause liver inflammation or damage. It may cause fairly severe bone marrow suppression. This has to do with the way the body metabolizes 6-MP. It is a convenient, oral pill that is taken on an empty stomach and absorbed best when there is no food in the stomach. As for how well it works in kids, we don't have any good large clinical trials yet. We do have small practice experience. Approximately 50-60% of those are treated at low dose and they were monitored every 2-3 weeks to check liver function and blood counts.

Bone Marrow Testing

Q: What are the requirements to do a bone marrow test in children?

A: DR. GEDDIS: If there is no reason to suspect leukemia, there is no reason to do a bone marrow test. Some doctors recommend a bone marrow test before treatment with steroids.

Genetic Links in ITP

Q: Is there new research on a genetic link to ITP or reason why family members would have ITP?

A: DR. GEDDIS: Probably not. The concept of inherited ITP is kind of complicated because in general we still believe ITP is not a familial (inherited) disorder but there are definitely inherited thrombocytopenias that are different from ITP but sometimes get misdiagnosed as ITP. There are also secondary forms of ITP that might occur in people who have an inherited immune disorder. The immune disorder itself is inherited and those people are prone to ITP.

Many people tell a story of multiple people in their family who have either ITP or some other autoimmune disorder. There must be something predisposing them to this. Two researchers looking into this are: Dr. Terry Gernsheimer, at the University of Washington *(http://depts.washington.edu/hemeweb/research/gernsheimer.htm)* and Dr. Drew Provan, in the United Kingdom, who has a Web site registry for people with ITP at *http://www.ukitpregistry.com/*.

Vaccines

Q: Any recommendations for immunization after my daughter's ITP was likely caused by the MMR vaccine?

A: DR. GEDDIS: This is a good question. Some published guidelines offer possible strategies for this. We know in a small percentage of cases (though

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2012 Showcases: PDSA 12th ITP Conference in Denver, CO

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conveniently located just 20 minutes from Downtown Denver and 30 minutes from Denver International Airport. Known as one of the area's premier conference resorts, this AAA Four-Diamond hotel boasts an award-winning golf course and spa, indoor and outdoor pools, walking and jogging trails, extensive fitness center, five distinct restaurants, and 302 newly renovated guestrooms and suites.

With its convenient location, The Inverness Hotel and Conference Center offers easy access to the city's many cultural, dining and entertainment attractions. The hotel is also just up the street from world-class shopping and dining at Park Meadows Retail Resort, and a comfortable drive from the picturesque towns and year-round recreation within the majestic Rocky Mountains. For those who arrive a few days before the conference or who stay a couple days later, there are many activities for guests and their families to enjoy in and around the area, including: Historic Larimer Square, Centennial Family Fun Center, Denver Museum of Natural History, Denver Botanic Gardens, Denver Art Museum, Denver Zoo, Coors Brewery, Colorado Springs, and Rocky Mountain National Park.

The Inverness Hotel Reservations

Staying at The Inverness Hotel, guests will experience the finest hotel accommodations. All guest rooms and suites offer complimentary hotel wireless internet access, pillow-top mattresses with plush comforters and pillows, and eco-friendly bath products. Free parking for conference guests is also included, along with free shuttle service within a five-mile radius of the hotel.

A block of rooms has been reserved at The Inverness Hotel for our ITP conference at a special rate of $99 single or $109 double per night. That rate is also available for attendees for three days prior to and three days after the conference dates. This special rate is available for reservations that are made by **June 15, 2012.** Rooms at the special rate may be reserved by calling 1-800-346-4891 and refer to the group **Platelet Disorder Support Association** or **PDSA** to book, or go online at *http://www.pdsa.org/conference.htm* to The Inverness Hotel link. Online, you can click on the following link: *https://resweb.passkey.com/go/PDSA*. If you have any problems, please contact us for assistance. We urge you to book your room as soon as possible. Hotel check-in time is 3 p.m. and check-out time is 12 p.m.

This year's three-day ITP conference program will feature renowned authors, researchers, and clinicians, all with strong interests in helping ITP patients improve their health. We have received commitments from some of the world's top ITP clinicians and researchers, including Drs. James Bussel, Douglas Cines, Terry Gernsheimer, Andra James, Craig Kessler, David Kuter, Howard Liebman, John Semple and Michael Tarantino. You don't want to miss this year's meeting! Each year the conference provides opportunities to hear the latest information about ITP, connect with others affected by ITP, and receive answers to your questions.

Some of this year's sessions include:

- **ITP Myths and Misconceptions**
- **ITP Treatment Update: What the Data Tells Us**
- **Patient Care in Practice** (real cases submitted by patients)
- **Does It Run in the Family?**
- **TPO Trials in Children**
- **Treatment Options to Reduce the Risk of Bleeding**
- **What to Do When Nothing Works**

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2011 ITP Conference DVD/CD Set Is Available Now

You can see and/or hear the presentations from the outstanding 2011 ITP Conference in Boston. This set of DVDs and CDs will include a copy of the conference program booklet.

Some of the topics included in this set are:

- "What the Recent ITP Guidelines Tell Us" by Dr. David Kuter
- "Does It Run In the Family?" by Dr. Amy Geddis
- "Treatment Options That Can Reduce the Risk of Bleeding in ITP Patients" by Dr. Craig Kessler
- "Living with ITP" by ITP patients who share their stories of hope and recovery
- "Diagnosis and Standard Therapy for ITP" by Dr. Terry Gernsheimer
- "For Teens Only" by Dr. Michael Tarantino
- "How Do We Know What Treatments Work: Clinical Trials and You" by Dr. Howard Liebman

Cost of each DVD/CD set is $50 (plus postal shipping, which varies by location and costs are higher outside the US)

To order your set, visit our Web site: *www.pdsa.org* and click on the "Platelet Store" or call us toll-free at (877) 528-3538.

2012 Showcases: PDSA 12th ITP Conference in Denver, CO

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- **Future Developments in Novel Agents to Treat ITP**
- **ITP and the Female Lifecycle**
- **ITP in Adults**
- **ITP in Children**
- **For Teens Only**

Question and Answer sessions usually follow each presentation.

Your conference registration includes continental breakfast on Saturday and Sunday morning, a catered box lunch and beverage on Saturday, and a special event with food and beverages on Saturday evening. Watch for details soon of this year's festive Saturday evening event!

Registration

Early Registration for this year's conference is now open through June 15th. Registration for PDSA members is $115.00 per person, or $185.00 for a family of two. Rates will be higher after June 15th. For non-members early registration is $135.00 per person, or $220.00 per family of two. Please consider joining PDSA before registering for this year's conference. You will receive the lower registration rate. Your support is greatly appreciated. In addition, Circle of Hope members and Support Group Facilitators receive free registration.

Registration can be done online, by mail or fax, or by phone. For online registration visit our Web site: *www.pdsa.org* and click on the conference button. To register by mail or fax, download our ITP Conference 2012 registration form. Complete and fax it to the PDSA office at 301-770-6638 with credit card information or mail it to our office at:

PDSA
133 Rollins Avenue, Suite 5
Rockville, MD 20852

(Checks, payable to PDSA, *should be in US funds, from a US bank only. Thank you.)*

To register by phone, please call the PDSA office at **877-528-3538** (toll free). We will be happy to assist you in gathering your conference and registration information. More details on the conference and registration information will be sent to all members in the next month — watch your mail. For more information on the conference and updates, and to register, please visit our Web site at *www.pdsa.org*.

ITP Conference 2012 may be our best meeting yet. We are looking forward to seeing you this summer in Denver!

Shopping on Amazon.com?

If you buy from Amazon.com, here is an easy way to help out PDSA. Go to the PDSA Web site at *pdsa.org*, click on 'Support PDSA', then on the Amazon link in the drop-down box 'Giving to PDSA'.

When you order your products, PDSA will receive a small percent of the purchase price. You pay the same low price for your items, and PDSA receives a valuable contribution from Amazon.com.

ITP in Adults: Q&A with Dr. Bussel

These are answers to written questions patients submitted to our panelists at the 2011 ITP Conference session "ITP in Adults Q&A". Since we ran out of time and did not get to all of the important patient questions, PDSA appreciates that Dr. James Bussel, panelist, and PDSA Medical Advisor, has kindly taken time to provide the answers.

Are there clinical trials involving Nplate® and prednisone; is it safe to take both?

There are no clinical trials specifically looking at the combination of Nplate and prednisone. The two have been used together in previous and ongoing clinical trials because you could have been taking prednisone when you started an Nplate® trial. It is fine and some people on Nplate eliminate the prednisone but some do not. It is definitely safe to take both. It is also unlikely to quickly get immune to prednisone but typically, even for people who are very sensitive to its effects, if they take it for a long time or repeatedly over a long time, prednisone will start to lose its effects in that person and it will have less and less effect over time. This is very variable individual to individual and usually takes a long time to occur if someone is very steroid sensitive in the beginning

A 55-year-old man has had ITP for 8 years, has a platelet count of 10,000/µl and has tried everything except splenectomy and the two thrombopoietic agents. His liver is enlarged. He wants to know what to do.

My general attitude for any patient with ITP who has other issues of any kind is to make sure that I understand the other issues first because they may impact the ITP. Conversely treatments of ITP may affect them. If the liver is enlarged because of prolonged steroid use (seems likely if he has had ITP for eight years, has a low count, and has never tried some of the other treatments) then that would be okay if it's "a fatty liver". It would be a major incentive to make sure that a gastroenterologist has evaluated this carefully and to not use any more steroids in the future. We would probably also need to consider diabetes and other issues like that in the evaluation prior to starting treatment. In general, if you were going to choose between Nplate®, Promacta®, and splenectomy in this patient you might be slightly less inclined to use Promacta if the liver is abnormal anyway even if it is a fatty liver. I am totally unaware of any data on this and it certainly could be used as long as the liver tests were monitored.

I think it would potentially make sense to start with Nplate and see what is going on with the liver, make sure you have a chance to have a complete evaluation, and then see what the response is. It would also depend on if the patient could get home care and how they were getting their injections. Splenectomy would certainly be an important consideration provided it was clear that there was not *hypersplenism* (an enlarged overactive spleen because of liver disease causing increased pressure in the spleen) or some other intrinsic liver disease.

There is a general question about recommendations for an adult with a platelet count below 30-50,000/µl who is receptive to taking prednisone.

Two main points about prednisone; one, you typically can't start at 5 mg/day even if that may work eventually. You need to start at a higher dose and taper down slowly. I think almost everybody would think that 5 mg/day of prednisone is an acceptable dose for most patients. If somebody is very sensitive to it and wants to take it and starts with say 60 or 40 mg/day, waits to get an effect and then tapers down to 5 mg/day and that works there is usually no reason why you cannot stay on that. There are some people who do not like it and others who cannot tolerate even that dose and they require a change to another medication.


Dr. James Bussel at the ITP conference, wearing the 'Hemoduct' tie designed by ITP patient, Beth Halem. The ties, with a design depicting platelets in the bloodstream, were given to this year's speakers.

Next is a question about splenectomy as treatment for ITP.

This remains a very good treatment. The bottom line on splenectomy though is that people on Web sites, waiting rooms, and other ITP-related activities who have had splenectomy will be the ones in whom it failed. If taking out the spleen succeeded, at most you are going to your doctor once a year and you are not usually spending a lot of time worrying about your ITP.

There is a question about splenectomized patients and bacterial infections.

In general, the most common cause of an overwhelming blood stream infection after one has had a splenectomy is from something called pneumococcus *(Streptococcus pneumonia),* which is a type of strep. The best way to prevent, avoid

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ITP in Adults: Q& A with Dr. Bussel

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and treat it are: a) get pneumococcal vaccine every 5 years and check the response to it by having blood sent for antibody levels; b) have antibiotics at home so if anything happens they can be started immediately; and c) plan to go to the emergency room immediately at any time there is a fever of 101°F or higher no matter how you feel. Do not wait to see if the fever responds to Tylenol® and do not wait until the morning. If the fever happens at 3 a.m. you should be leaving home at 3:05 a.m.

Part of this means that you need to have a thermometer handy and you need to take your temperature whenever you feel sick even if you do not feel very warm. Ideally when you get to an emergency room, a blood culture would be done, a blood count would be drawn, your blood pressure and things like your temperature, pulse and respiration (breathing) rate would be assessed and ideally you would get an antibiotic such as Ceftriaxone right away. You need to be observed. Many physicians recommend antibiotic prophylaxis (usually penicillin) to be taken daily for life after splenectomy.

There is a question about taking prednisone, 5 mg every 10 days.

There are very rare patients whose platelets are amazingly sensitive to very infrequent prednisone. Nonetheless, most of us would believe that in this case, you probably don't need further therapy. The simplest way to work with that would be to taper it further slowly and see what happens. For example, take it once every two weeks for 3 months, then once every 3 weeks for 3 months maybe even once every 4 weeks for 3 months and if your platelets are still good, then you could stop it. At 5 mg every 10 days the toxicity is small so there is no real reason to rush into this tapering plan but you certainly could do this.

There is a question about susceptibility to infection on prednisone.

This is not very clear. On the one hand, we think that prednisone suppresses immunity; on the other hand the dose of prednisone matters a good deal. Furthermore, prednisone suppresses inflammation so someone might be infected but have a less severe infection since some part of the illness is related to the inflammation of the body reacting to the infection. One published report in particular suggested there was a small increase in serious bacterial infections in patients on long-term, too high dose steroids.

A question as to duration of ITP.

There are patients who have had ITP more than 40 years and it is still very active. In other people after 10 to 20 years it so-called 'burns out' meaning it improves spontaneously.

The question about allergy and ITP is a real hot topic.

The UK group is doing specific studies of food allergy. We hope to do a study through PDSA of other forms of allergy or sensitivity. The actual issue is not very clear but if you know you have allergies, e.g. to a food such as strawberries or shell fish, or your family member with ITP has allergies, it is probably worth trying to see if avoiding those is helpful.

The next question involves ITP and clotting in the legs, along with a genetic marker for it.

This was discussed at the conference but the main item would be that taking blood thinners and having a platelet count greater than 30-50,000/μl to allow doing that is probably the right way to go rather than relying on just a

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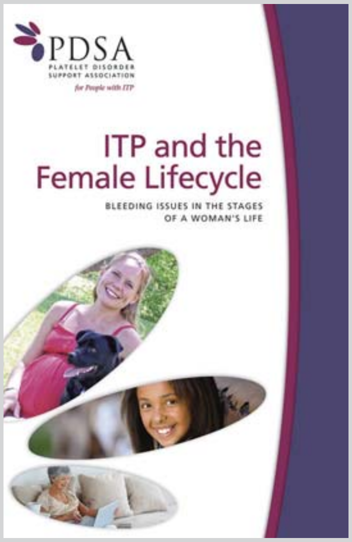
New *ITP and the Female Lifecycle* Booklets Now Available

PDSA's newest booklet "ITP and the Female Lifecycle: Bleeding Issues in the Stages of a Woman's Life" is now available. The new patient information booklet covers ITP and bleeding issues in a woman's lifecycle from childhood, teen years, child-bearing years, menopause, and beyond. It includes extensive information for ITP and pregnancy. Be sure to get your copy soon.



Copies of the new booklets are available to download free from the PDSA Web site at: *www.pdsa.org*
Click on 'Products and Publications' and then 'Free Materials'.

You can also request print copies of the booklets by calling PDSA, toll-free 1-877-528-3538 or by sending an e-mail request to: *pdsa@pdsa.org*

PDSA thanks **Amgen** for their healthcare donation that made possible the production of this new booklet.

News from Our Support Groups

Our 32 local support groups and one teleconference group are the empowering grassroots that combined with our national partners and outstanding medical advisors create the opportunity for PDSA to enhance the lives of those affected by ITP and other platelet disorders. It's this strong network that will continue to create awareness, educate, and advocate. Here are some inspirational stories we've received from our support groups recently. To share your news, please contact Nancy Potthast at: *npotthast@pdsa.org*

NEW Miami, FL ITP Support Group

Facilitator: Barbara Pruitt
(barbarap23@bellsouth.net)

We're excited to announce there is a newly formed group in the Miami, FL area! Please contact Barbara Pruitt either by email: *barbarap23@bellsouth.net* or phone: 305-409-6887.

Detroit, MI ITP Support Group

Facilitator: Sharon Cisco
(itpdetroit@yahoo.com)

At the November 19th meeting of the Detroit, MI the Support Group watched a portion of the PDSA Conference 2011 DVD and shared their stories. The group also has its own group page on Facebook — itpdetroit. Check them out!

The next meeting will be held on Saturday, March 24th, from 9am – Noon.

Phoenix, AZ ITP Support Group

Facilitator: Joan Young
(youngjoanw@gmail.com)

At the December 10th meeting Joan Young gave an update from the recent American Society of Hematology (ASH) Conference she attended in San Diego. The support group attendees were very interested to hear about the new treatments, additional information about TPO agents, and the implication of new genetic findings. Group members also shared experiences and information about the strengths of some local doctors and hospitals.

The next group meeting will be held in March. Check the Phoenix Support Group page at *www.pdsa.org* for more information.

Cleveland, OH ITP Support Group

Facilitators: Barbara Hise
(fourstrings@ameritech.net),
Caroline Kruse *(kencaroline@att.net)*

The January 12th meeting had six of the group's regular members in attendance. Group members debated the pros and cons of vaccinations for ITP patients, including the flu and pneumonia vaccine. Support was offered for one member whose teenage son has been through most of the available ITP treatments with no success. The upcoming PDSA National ITP Conference was also on the agenda, with members excited about this year's meeting in Denver, CO.

The next meeting will be held on Thursday, March 22, from 7pm-8:30pm.

Joan Young is the facilitator for one of our newest ITP Support Groups, in Phoenix, Arizona. She shared the following comment she received from a local Phoenix member regarding PDSA's online patient booklet "Health Insurance Assistance Programs for ITP Patients":

> "This is an extremely well written brochure. I wish we had something like this in the dialysis field where I work."

The booklet (and many others) can be viewed at: *http://www.pdsa.org/products-a-publications/free-materials.html*

PDSA Offers New Online ITP Forum for Men

Due to patient requests, we have created a new discussion group on our Forum for men. We already had a discussion group for women, since there are issues related to ITP which are unique to women. We are pleased to announce the MAN CAVE is now open for business.

Man Cave: *http://pdsa.org/forum.html*

If you want to discuss issues specifically for MEN, come hang out in the Man Cave.

PDSA Local Support Groups

PDSA has support groups across the United States and Canada and new groups continue to form. Listed below are existing groups with meeting dates. No group listed in your area? Consider forming a group and becoming a facilitator. We'll provide you with a New Facilitator Kit to help you get a group started. Just contact Nancy Potthast at *npotthast@pdsa.org* or call toll free at 1-877-528-3538. ***For information on meeting locations, dates, and times please contact the group facilitator.***

ITP PARENTS TELECONFERENCE GROUP
Facilitator: Jay Charness, *jay@ape-strangerawareness.com* or (303) 731-7731
2012 Meeting Dates: February 8, April 4, June 6

OTTAWA, ONTARIO – CANADA
Facilitator: Livia Chyurlia and Vanessa Carroll, *pdsa.itp.ottawa@gmail.com* or (613) 612-9689

PHOENIX, ARIZONA
Facilitator: Joan Young, *youngjoanw@gmail.com*
Meetings will be held quarterly. Please visit the support group page on *www.pdsa.org* for exact dates.
2012 Meeting Date: March 10

LOS ANGELES, CALIFORNIA
Facilitator: Maryam Azarbayjani, *mazarba@calstatela.edu* or (310) 447-1629

PATTERSON, CALIFORNIA
Facilitator: Carla Nelson, *carlanelson5@gmail.com* or (209) 892-8813

SAN DIEGO, CALIFORNIA
Facilitator: Susan Pounder, *suekui@yahoo.com* or (858) 217-6587

WASHINGTON, D.C.
Facilitator: Diane Joseph, *dianej74@cox.net*

MIAMI, FLORIDA
Facilitator: Barbara Pruitt, *barbarap23@bellsouth.net;* (305) 409-6887
Please contact Barbara via email or phone for first meeting date and location.

NORTH FLORIDA
Facilitator: Irene Xynides-Rincon, *xynidesi@bellsouth.net;* (904) 710-9055 or (904) 823-9055

TAMPA BAY, FLORIDA
Currently looking for a new facilitator

ATLANTA, GEORGIA
Facilitator: Wendi (Gilbert) Van Eldik, *wendi.gilbert@gmail.com* or (404) 317-1173

SOUTHEAST, GEORGIA
Facilitator: Patricia Johnson, *triciagdawn@yahoo.com* or (229) 247-0699

CHICAGO, ILLINOIS
Facilitator: Trish Beattie, *chicagoitpsupport@comcast.net* or (630) 292-1485, *http://chicagoitpsupport.home.comcast.net*
2012 Meeting Dates: April 21, July 14, November 10

DETROIT, MICHIGAN
Facilitator: Sharon Cisco, *itpdetroit@yahoo.com* or (586) 783-8014
2012 Meeting Dates: March 24, May 19

OMAHA, NEBRASKA
Facilitator: Heidi Green, *bgreen6833@cox.net* or (402) 498-3826

CENTRAL/NORTH NEW JERSEY
Facilitator: Linda McGuirl, *LindaMcguirl@aol.com* or (908) 580-9572

NORTH NEW JERSEY
Facilitator: Dianne Danielle, *sonnydeeb@aol.com* or (201) 265-8875 and Lanie Gastman, *lanieg45@aol.com* or (210) 592-1181
2012 Meeting Dates: February 2, April 5, June 7, August 2, October 4, December 6

SOUTH NEW JERSEY
Facilitator: Michael Vitale, *mvitp@comcast.net*

CAPITAL DISTRICT (ALBANY AREA), NEW YORK
Facilitator: Jill Bailie, *pdsacapitaldistrictny@yahoo.com* or (518) 882-9700

LONG ISLAND, NEW YORK
Facilitator: Claudia Montuori, *roadmap5@verizon.net* or (718) 725-2645

CHARLOTTE, NORTH CAROLINA
Facilitator: Carol Mullis, *carolhmullis@windstream.net* or (704) 843-2734

CINCINNATI, OHIO
Facilitators: Mary and Mark Griffith, *mmgriff5@hotmail.com* or (513) 922-4255

CLEVELAND, OHIO
Facilitators: Barbara Hise, *fourstrings@ameritech.net* or (216) 752-8051 and Caroline Kruse, *kencaroline@att.net* or (440) 526-0629
2012 Meeting Dates: March 22, May 24, July 12, September 13, November 8

DAYTON, OHIO
Facilitator: Tina Garland, *tgarland@woh.rr.com* or (937) 643-1705

PHILADELPHIA, PENNSYLVANIA
Facilitator: Michael Westfort, *michael@platelethealth.org* or (484) 461-9599

POCONOS, PENNSYLVANIA
Facilitator: John Catalano, *johncatalano@hotmail.com* or (917) 892-4264

CHATTANOOGA, TENNESSEE
Facilitator: Sharon Putnam, *sharonputnam@att.net* or (423) 991-6450

SWEETWATER, TENNESSEE
Facilitator: Christy Champ, *pdsa_sweetwater@yahoo.com* or (423) 920-4660

NORTH, TEXAS
Facilitators: Linda and Kris Dorasami, *krld@flash.net* or Linda (817) 727-2351 or Kris (817) 727-2361

SEATTLE, WASHINGTON
Facilitators: Tammy Fassett, *tcfassett@gmail.com* or (206) 465-3451 and Cathy Hendrickson, *Cathyh613@gmail.com* or (206) 764-7128
2012 Meeting Dates: April 21, July 21, October 20

FAIRMONT, WEST VIRGINIA
Facilitator: Camie Sims, *camie1222@aol.com* or (304) 534-8768

MILWAUKEE, WISCONSIN
Facilitators: Kim Everett, *wipdsa@gmail.com* or (920) 755-8430 and Trudy Sensat, *wipdsa@gmail.com* or (414) 202-6291
2012 Meeting Dates: May 19, September 15

What Our Friends Are Saying

HERE IS A SAMPLING OF NOTES RECEIVED RECENTLY

Dear PDSA,
I am truly grateful for the doctors who helped me deliver three beautiful, healthy children while suffering from chronic, severe ITP. (It's hard to believe my children are now 22, 21, and 18!) I am also very grateful to PDSA for adding support and education along my journey with ITP. I have met some great people as a result of the PDSA network and local support group. Best of Health and Happiness to all in 2012!
Linda M

Dear PDSA,
Thank you to Caroline and all the staff at PDSA. You have been my beacon of light during a very dark time. Peace and Joy!
Barbara R

Dear PDSA,
I would like to thank you for your work involving every aspect of platelets. I'm donating $500 to PDSA at this time.
Thanks, *Barbara T*

Dear PDSA,
I am so appreciative of your thorough response. Indeed, my brother-in-law was waiting for Dr. Ahn at the University of Miami. And a wonderful thing happened. When Dr. Ahn heard of my brother-in-law's difficult case, he agreed to come in to the University to examine him. The examination occurred last Friday. He has taken his case and has ordered very specialized tests for him. In the meantime, his original physician, Dr. Golstein had followed the standard protocol for treatment of ITP and ordered the Nplate® after everything failed to raise his platelet count above 17,000. Dr. Goldstein ordered treatment for *H. pylori* bacteria because he was suspicious of some of the test results he was seeing. After 3 Nplate shots, and treatment for the *H. pylori* bacteria, my brother-in-law's platelet count is now currently in the 400,000's — the first good piece of news we have had after more than three weeks of bad news. We are all elated.

I cannot stress how much your Web site has provided me with the vital information that I needed to assist and reassure my sister and her husband through this medical crisis. Organizations such as the pdsa.org are the beacon of hope that people in distress desperately need. I cannot thank you enough.
With great appreciation, *Renee F*

Dear PDSA,
I would like to receive the most recent newsletter and I did want to purchase a membership to PDSA. If that already includes the most recent newsletter, could I have the two most recent ones? Thanks so much for your help. In the few weeks since my daughter's recent diagnosis of ITP, I have found your organization and your Web site tremendously informative and reassuring. Thanks for all you do.
Trish

Dear PDSA,
A big thank you to John, he was most helpful. I was diagnosed with chronic ITP in Jan 2010. I was fortunate to have remission for 18 months and relapsed a month before my wedding. I have not been a responder to many of the treatments so this has been an uphill battle at the age of 26 but the resources of PDSA have been so helpful to me and my family. I wish we could afford to give more, but the medical expenses continue and I continue to be out of work as a nurse. Thank you for all of the support of PDSA!
Melissa

Dear PDSA:
I would like to donate a portion of my check to you through my work — United Healthcare - United Giving Campaign. Anything to aid in the research and "idio" of chronic refractory ITP. Please know that there was a multitude of other treatments I tried before I resorted to the Vincristine and Cytoxan; prednisone, decadron, aziothioprine, rituxan, splenectomy, just to name a few. I hope this helps anyone.

I found your site when I was in my 3rd year of ITP and trying to navigate through all the medications and trials. Finally, five years ago, I did a round of Vincristine and Cytoxan and after 6 months my ITP went into remission. I since have been discharged from my hematologist and things are much better. I don't think I would have made it through without your Web site to not only talk with others but also to find out more about new medications. You were and continue to be a "God send".
Thank you, *Anne S*

Hi Caroline,
Thanks for the card. I have been a member since about 2001. So I do remember the early days of PDSA. I got lots of help early on in my diagnosis from the chat board. A lot of the folks with whom I chatted are no longer active members, but they sure did help me through hard times and lots of decision making. I don't frequent the boards anymore, but I am still plugging along, and thanks to NPlate, my counts remain steady!
Happy holidays, *Monica*

Caroline,
PDSA has helped me more than I can say. I am so grateful that this

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> "After 3 Nplate® shots, and treatment for the *H. pylori* bacteria, my brother-in-law's platelet count is now currently in the 400,000's — the first good piece of news we have had after more than three weeks of bad news. We are all elated."
>
> – Renee F.

What Our Friends Are Saying

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organization kept me informed of the latest treatments and saved me from disaster of steroid treatments. They were totally contraindicated and caused undue harm before I convinced the doctors I could not take the drug. CHRISTMAS BLESSINGS AND JOYFUL NEW YEAR
Rae Ellen

Hello Carol,
Thanks so much for this information. This and the PDSA website has been such a great help as we learn and cope with my father's diagnosis.
Best Regards, *Michael O*

Dear PDSA,
I have ITP. I have had this disease since I was 4 years old. I am now 28. Everyday is a struggle, but I keep a smile on my face and stay encouraged that one day there will be a cure for ITP.
Best Wishes, *Erica J*

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, 133 Rollins Ave., Suite 5, Rockville, MD 20852, or via e-mail to pdsa@pdsa.org. *Letters may be edited for length and clarity.*

> "Five years ago, I did a round of Vincristine and Cytoxan and after 6 months my ITP went into remission. I since have been discharged from my hematologist and things are much better.
> I don't think I would have made it through without your Web site to … talk with others … to find out about new medications."
>
> – Anne S.

Making A Difference

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Barbara Pruitt (wearing jewelry she created) with PDSA Board members Jamie Harwell (L) and Beth Siegelbaum (R)

annual ITP conferences. She considers her jewelry sales as her artistic outreach on behalf of others with ITP and on behalf of PDSA. To help spread awareness, Barbara brings ITP patient brochures and booklets to her jewelry sales that she shares with visitors who stop by.

Barbara's work for PDSA is never done; she recently started a new ITP patient support group in the Miami, FL area. She also takes many of the calls from ITP patients that PDSA receives each month. Because of Barbara's involvement with PDSA at so many levels, from her membership in the Circle of Hope, to attending the ITP conferences, sharing her ITP experience as a speaker, volunteering, attending the ASH conferences, starting a Miami support group, and producing and selling her jewelry to benefit PDSA, she has made a huge difference in the lives of so many others who are coping with ITP themselves.

Tell us about someone you know who is making a difference. Contact Carol Hoxie at rchoxie@pdsa.org.

A Different View

Unusual Success Stories from Our Mailbox

The information in this section is a personal view. It does not represent an endorsement by PDSA or its medical advisors. For advice on your unique medical condition, please consult your health care provider.

Dear PDSA,
Just wanted to let you know that Fosamax (Alendronate Sodium, a biphosphonate drug used to treat and prevent osteoporosis) can lower platelet counts. I had no idea of this while on it. I stopped 18 months ago. Looking back at my records, my lowest platelet counts were while taking it. (Previously they were 50,000 to 60,000, then 20,000 to 30,000 while on it, now back to 50,000 to 60,000s). This info needs to get out there, as so many women are on bisphosphonates! Thank you, as always, for all the great work you do. I've been a very grateful member for years! *Jacquelin*

After PDSA sent her some links to NIH Web sites for further information, Jacqueline sent this follow up note:

Hi Carol,
Thank you for this information. The first link you sent (the NIH one) specifically states "tell your doctor"… if you have "any condition that stops your blood from clotting normally." So there it is. Incidentally, I myself am a Nurse Practitioner, but not in primary care. I never saw this before, and happened to come across something raising the question, so I Googled it and found other citations for association between bisphosphonates and lowered platelet counts. So I don't think I'm alone (or unique) here. Perhaps this is something to bring to everyone's attention? Feel free to use my comments in your newsletter. I'd say, let's get the word out, to at least make people aware of the possibility and consult with their providers. Thank you!!
Sincerely, *Jacquelin*

Editor's note: PDSA has now added Fosamax to our Warnings page on the PDSA Web site: http://www.pdsa.org/about-itp/warnings.html

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Dear PDSA,
I am a former ITP patient. I do not prefer the term "remission." I like to think that I am healed/cured. I credit that success in part with your Web site, *ITP People,* in 2002. I gathered advice from one of the patient's success stories, then I tried it, and it seemed to work. I also give credit to prayer. (Well, something definitely worked!)

I was diagnosed in November 2000 when it was discovered I only had 1,000 platelets. I never had my spleen removed. I just took prednisone until I read that success story. The patient was advised to try a raw adrenal cortex solution, so I went to my local health food store and purchased a comparable product. Soon, my platelet count seemed to rise with less prednisone (mg doses). By early 2003, I was fully weaned off prednisone as my platelet count stayed within the normal range. The last time it was checked this year, it was over 250,000. I have been well since early 2003. It was as if I only had it for two years, and I was 25 when diagnosed.

Doctors say that it is normally a chronic condition for adults. One doctor told me that it will come back, so I don't go to him anymore. Since 2006, I have had two babies and did

(CONTINUED ON PAGE 27)

"You know about PDSA but does your hematologist?"

The Platelet Disorder Support Association (PDSA) would like hematologists to know about our work. We have prepared packets of our materials including a letter introducing PDSA, copies of our ITP publications (ITP brochure, *ITP in Adults* – English and Spanish, *ITP in Children* – English and Spanish, *ITP in Teens, ITP & Pregnancy,* and *Coping with ITP*), *"When a Child Has ITP": a Resource Guide for Parents,* a copy of our quarterly newsletter, and other information about PDSA's work to support ITP patients. Physicians may then request additional copies of these booklets and materials.

Please help us inform more hematologists about PDSA's programs and publications by taking a packet of information to your physician. You can get a packet to take to your doctor by filling out the form below and returning it to us at:

PDSA • 133 Rollins Ave., Suite 5,
Rockville, MD 20852

If you prefer, you can call 1-877-528-3538 (toll-free) and ask for a packet to be sent to you or send an email to *pdsa@pdsa.org.* We will then send a packet for you to take to your physician.

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Global View

Letters from Our International Friends

PDSA' S SUPPORT REACHES BEYOND THE U.S.
HERE IS A SAMPLING OF NOTES PDSA RECEIVED RECENTLY FROM OUR INTERNATIONAL FRIENDS

The following Case History appeared in the September 2011 issue of The Platelet, *a publication of the UK's ITP Support Association. It is reprinted here with permission of the ITP Support Association and of the patient, Sara.*

My name is Sara and I am 16 years old. When I was seven years old, I was diagnosed with chronic ITP. At the time of my diagnosis, my platelet count was at 11,000 *(in the UK, this would be a count of 11. –Ed)*. The first six months I had IVIg treatments once a month. During the first year, I was very sick with strep throat infections every two weeks for four months. There were a lot of antibiotics during that time. At the end of my first year, my count was around 30,000.

During my second year of having ITP, I cut back on refined sugars, and that helped my platelet count rise to 50,000 to 60,000. My parents took me to a naturopath to have my allergies and sensitivities tested. I found out that I was sensitive to corn, gluten, dairy, and food dyes. After removing those from my diet, especially the corn and corn derivatives, my platelet count was up to 80,000 to 90,000 that year.

Half way through my third year of being diagnosed with ITP, my parents found a holistic chiropractor who looked through my medical records and suggested analyzing my stool to see if there was an appropriate balance of bacterial flora. It turned out I didn't have any lactobacillus. I was treated for intestinal flora imbalance, which helped my count increase to over 103,000.

During the fourth and fifth year, I was tested and treated for hormonal imbalance and insulin resistance. That plus all the changes I had made in the previous years helped my immune system to reset itself. The next two years that followed, my platelet count still steadily increased. When I was 14, I received a clean bill of health, with my platelet count being 175,000.

I know that all cases of ITP are not the same. Having a healthy diet will be beneficial for all of us, and I believe that my change in diet truly helped my platelet count rise. Thank you for giving me this opportunity to share my story, I hope this could give others who are struggling some encouragement.

PDSA, Hullo again.
Well, I'm now home after 28 days in hospital. I awoke on Tuesday, 02/08/2011, at about 7:30 a.m. to find I had a bleed. I saw my pillow covered in blood, as well as my mouth and face. No fun. It had scared the hell out of me. My doctor had also phoned me as I woke with the order from him to "get to Hospital asap as my platelets had dropped to just 3,000." I arrived at the Emergency Department (ED) at the Fremantle Hospital in Western Australia. After seeing a doctor in the ED and blood was taken, my platelets had dropped to 1,000. I was placed in hospital where I remained for 28 days. I received IVG INTRAGAM and steroids. A red blood cell scan was also ordered to see if I had another spleen. My first spleen had been removed on 08/31/2010. This other spleen they found was removed 08/14/2011. I received blood platelets just before the operation and during the operation. After the operation another red blood cell scan was done to see if there were any other spleens. I was given the all clear, (happy to hear). I was given another IVG INTRAGAM infusion and then treated with rituximab when my platelets dropped again to 2,000. I was infused with more INTRAGAM and then platelets. Then my platelets went up to 62,000. I was sent home, with appointments to return to the day clinic at the same hospital each Friday, for now. I am a 52-year-old man and live in AUSTRALIA, in the state of Western Australia, in the city of Perth, a suburb of Rockingham.

Thank you, *Chris D*

PDSA welcomes your letters and thanks you for taking the time to write. We love to hear from you. Please send your letters to Global View: Letters from Our International Friends, PDSA, 133 Rollins Avenue, Suite 5, Rockville, MD 20852, USA, or via e-mail to pdsa@pdsa.org. *Letters may be edited for length and clarity.*

Want to Meet Others?

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For more information see *www.pdsa.org/nameex.htm* or call us toll-free at 877-528-3538

News from the American Society of Hematology Meeting

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years, providing large databases of patient experiences. The companies continue to gather, analyze, and publish data on the treatments' long term efficacy and safety. A similar product Rh-TPO (TPIAO®/Sunshine Pharmaceutical Co Ltd, China) is also available in some countries, but less is known about it in the US.

Extended studies of eltrombopag and romiplostim demonstrate that the treatments work well. In an international study of romiplostim, the largest to date with 407 patients, 90% of the people in the clinical trial achieved the desired response from the treatment in about two weeks, regardless of splenectomy status (#3279). Several researchers reported that a small number of people in romiplostim trials were able to maintain a safe platelet count after the treatment was discontinued, demonstrating that continuous use is not always required for remission (#3281). Additional results of the EXTEND study of eltrombopag, an on-going, open-label study, showed that 88% of participants achieved a platelet count of greater than or equal to 50,000 at least once and, for most, bleeding symptoms were markedly reduced (#3296).

Eltrombopag may be a good treatment choice for the most refractory patients. In a study comparing the number of previous treatments with a response to eltrombopag, people who had four or more prior treatments responded as well as those with fewer prior treatments (#3297). These treatments may also be a good choice for some children. Doctors analyzed the records of children (younger than 21) given either eltrombopag or romiplostim from two centers. Of the 32 children tested, 62% achieved a platelet count greater than 50,000 on at least two visits. Of particular interest is that the younger children didn't respond as well as the older children (#2230). Since people with ITP over 65 have a greater chance of developing a spontaneous hemorrhage, researchers wanted to determine if eltrombopag was safe for that age group. They separated the records in previous clinical trials by age and found no significant difference in safety or efficacy in the older vs. the younger patients, although there were more thromboembolic events in the older group, which was expected (#3294). In a study comparing experience with the TPO agents when switching therapies, the patient surveys showed little difference between the two treatments, however the patients taking eltrombopag did report somewhat greater convenience and overall satisfaction (#2220).

The safety concerns raised during and after the FDA approval process continue to be studied to determine the extent and degree of the problems. *Bone marrow reticulum*. In a study of eltrombopag, 180 bone marrow specimens, taken from 110 people treated for up to 4.5 years, were normal in more than 90% of the cases. None of the people who developed reticulum experienced adverse effects from the condition (#528). *Cataracts*. In a study of eltrombopag and cataracts, a special committee of ophthalmologists found "no evidence of an increased risk of cataract or cataract progression in chronic ITP patients treated with eltrombopag." They did note that prednisone is known to increase the risk for cataracts (#1164).

Liver toxicity. Eltrombopag can increase liver toxicity in some patients. Researchers theorized this was due to the similarity of the eltrombopag molecule with an acid that causes oxidative stress in the liver (#2238). *Thromboembolic (harmful blood clot) events*. Researchers compared the platelet characteristics of people

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FDA Eases Rules for Nplate and Promacta

As part of the approval process for Nplate (romiplostim) and Promacta (eltrombopag) the FDA mandated safety-monitoring (REMS) programs requiring targeted education and registration for patients, physicians, and pharmacists. The FDA has recently examined the safety data collected in the years since these treatments became available and concluded that the REMS program criteria could be relaxed. They eliminated the education and registration requirements, reducing the time and paperwork for everyone involved and potentially increasing access to these treatments.

More information can be found on our Web site here: *http://www.pdsa.org/home/latest-news/item/548-fda-announces-changes-to-risk-strategy-requirements-for-2-drugs-to-treat-low-platelet-counts.html*

PDSA' s Executive Director, Caroline Kruse, and Director of Marketing, Nancy Potthast, helped at the PDSA booth during this year' s ASH Meeting in San Diego, CA

News from the American Society of Hematology Meeting

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with ITP treated with steroids or eltrombopag, along with those receiving no treatments, to find something that would explain the increase in thromboembolic events in eltrombopag patients. They found no significant difference in the platelets of the two eltrombopag patients who developed blood clots and those who had none (#3280).

Companies continue to search for new treatments for ITP

The abstracts described preliminary clinical trials for two new treatments for ITP. Rozrolimupab, a combination of 25 unique human antibodies, is the first manufactured antibody mixture for the treatment of ITP. It works similar to anti-D in that it binds to red blood cells. In a trial of 61 participants measuring the safety and efficacy at different doses, 50% responded in 24 hours and 83% responded by day seven. The most frequently reported adverse events were headache and fever (#527). Veltuzumab is an anti-CD20 monoclonal antibody, somewhat similar to rituximab (Rituxan®), but given as a subcutaneous injection (under the skin). A total of 41 patients participated in the initial trial. Those who had ITP for a shorter time before treatment with veltuzumab had a better response than more refractory patients (#3302).

There is less emphasis on the benefits of splenectomy and more on predicting success

While many doctors feel that splenectomy is a good treatment option, the number of studies touting splenectomy success at the ASH meetings has waned. A California study compared the rate of blood clots in veins (VTE) and a dangerous infection (sepsis) for those ITP patients who were splenectomized versus those who were not. In the hospital records they examined, people with splenectomy were more prone to both VTE and sepsis than those who still had their spleens. Older people as well as those with other diseases were more apt to have problems (#3284).

Researchers compared the characteristics of spleens removed from people with ITP with spleens removed from trauma victims and found no differences in the spleens between the two groups (#3291). A French study looked at splenectomy success in children. Researchers found that splenectomies of younger patients, those under ten, were less successful. Isotropic platelet studies (indium screening tests) were done in 30 of the 44 children in 10 different hospitals in France to help predict splenectomy success (#2227). Some hospitals in the US are investigating the cost and effort required to offer the indium screen tests here.

Current treatments continue to be analyzed singly, in combination, and in comparison with each other

To compare the relative effectiveness of romiplostim (Nplate®), rituximab (Rituxan®), and other treatments, researchers used data from a romiplostim versus standard-of-care study and extracted the rituximab patients for further analysis. After comparing the safety and efficacy of romiplostim, rituximab, and other treatments, they found that romiplostim had a greater positive effect on platelet count than the other two approaches. However, the authors acknowledged it was a difficult comparison since romiplostim is designed as an on-going treatment and rituximab is not. Adverse events were similar for the three groups (#3282).

Patients treated with rituximab often relapse so doctors combined the rituximab treatments with several cycles of dexamethasone, a steroid similar to prednisone. At the eight-month follow-up, 65% of patients given this combination remained responsive. The adverse events were generally mild; however dexamethasone was poorly tolerated (#1166).

Chinese researchers tested a combination of rituximab and rh-TPO in 21 people. The combination produced a “higher overall and complete response, shorter TTR [time to respond] as well as higher sustained response” (#2223). TPO agents can be expensive and some countries with single-payer systems are hesitant to include them. Romiplostim is not currently included in the public reimbursement in Canada while IVIg, an expensive treatment frequently used there, is reimbursed; so Amgen undertook a cost comparison of the two treatments. Analysts determined that the annual cost for romiplostim is $47,244 versus $114,548 for IVIg, potentially saving treatment costs if romiplostim were used (#4211).

To test a different way of administering anti-D (such as Win-Rho® or Rhophylac®), doctors in Thailand injected anti-D into muscles (intramuscular) rather than veins. Those given a small dose for five days had a better response than the other schedules tested. There were no long-term remissions, but the authors did conclude this was a good treatment for a short-term rise in counts where anti-D is available (#3285).

Researchers are using genetics and other markers to help determine which treatments have a better chance of working

Both doctors and patients would really like to have a way of predicting which treatments are more likely to succeed, saving time, money, and avoiding the side effects of failed treatments. To help predict a response to TPO agents,

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researchers compared the thrombopoietin (TPO) levels of people with high platelets, low platelets, and with different diagnoses. They concluded that high TPO levels in people with ITP may predict a poor response to the thrombopoietin treatments (#3288).

Researchers also made progress in predicting the response to non-TPO treatments. They measured the various forms of Hβ-1 tubulin, part of the DNA required for platelet production, in people treated with TPO agents and non-TPO agents. They concluded that Hβ-1 tubulin with the R307H substitution led to increased platelet turnover and was associated with double the rate of treatment failures in the non-TPO treatment group (#525). To help predict response to steroids, researchers compared the type of anti-platelet antibodies in patients with their steroid experience.

In a study presented at the ITP breakfast, a researcher reported that patients with anti-GPIbα antibodies or with antibodies against both GPIbα and GPIIbIIIa had a poor response to steroids. People with these types of platelet antibodies also had a poor response to IVIg *(http://www.ncbi.nlm.nih.gov/pubmed/22139961).*

Researchers in Australia tested a lower dose of rituximab as well as did genetic testing to see if a particular type of the FcGammaR3A (FCGR3A) gene correlated with success. The abbreviated rituximab schedule had comparable efficacy to the longer schedule that is often used. However, the genetic testing was unable to predict success (#1157). Sometimes it takes awhile for platelets to rise after treatment. Researchers found that people with ITP had significantly less GPIbα, a protein shed from their platelets, than healthy controls. After treatment, the GPIbα approached normal levels before the platelets rose, making it a possible advanced signal for treatment success (#3289).

The impact of ITP on quality of life continues to be studied and appreciated

The most feared problem in ITP is intracranial hemorrhage (ICH), bleeding in the brain. To get a better idea of the rate of this event, researchers in California looked at hospital discharges with a diagnosis of ITP in state-wide hospital records from 1991 to 2009. They found that 2.67% of patients with ITP had an ICH, more than they expected. Older people and those with other health conditions were more susceptible (#1161).

An analysis of a large database of emergency room records showed that, in comparison to other diagnosis, ITP patients were "associated with significantly worse outcomes, higher resource utilization, and greater total charges." Younger age and ITP as the prime diagnosis were associated with better outcomes (#4209). A hospital study of ITP in children confirmed that ITP can be a complicated and costly disease to manage.

A large 2006 sample of hospital records showed that older children with ITP or those who had ITP associated with other diseases had longer lengths of stay, more splenectomies, and generally higher hospital costs than other instances of the disease (#170). In another study of pediatric hospital records, this one from 2008 to 2010, researchers found large geographic variations in the hospital cost, treatment strategy, length-of-stay, and likelihood of readmission. IVIg was the most commonly used therapy for children in all regions. Since the hospital records showed few bleeding problems, the authors conclude that most of these cases could have been managed without hospitalization (#341).

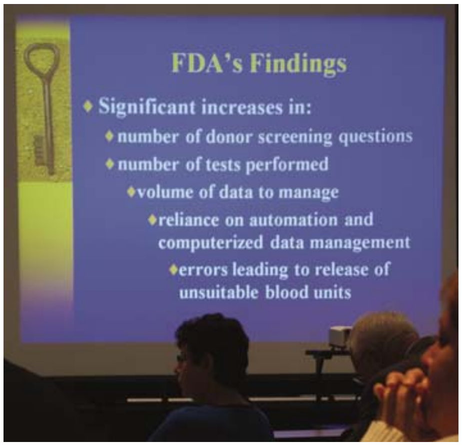
Watch for ITP Research Update from ASH, Part 2 in the spring issue.

Quarantine Release Errors in Blood Establishments: A Public Workshop

By Carol Hoxie

When a patient receives a blood or platelet transfusion, they are trusting that the blood product they are receiving is safe and won't cause injury. What is being done to insure that blood released for patient transfusions is safe?

On September 13, 2011, the Food and Drug Administration's (FDA) Center for Biologics Evaluation and Research, America's Blood Centers, and the Office of the Assistant Secretary for Health, of the Department of Health and Human Services (DHHS) sponsored a one-day workshop on quarantine release errors (QREs) in blood establishments. The public workshop provided a forum for discussion of QREs and provided FDA and the industry with information necessary to reduce the rates of QREs. PDSA attended the workshop, held in Rockville, MD, in order to stay aware of safety issues pertaining to our nation's blood supply and issues that might relate to ITP patients.



FDA's Findings

◆ Significant increases in:
- ◆number of donor screening questions
- ◆number of tests performed
- ◆volume of data to manage
- ◆reliance on automation and computerized data management
- ◆errors leading to release of unsuitable blood units

FDA and DHHS sponsored a one-day workshop in September 2011 on quarantine release errors in blood establishments

A wide range of speakers including experts from the FDA, blood centers, several hospital transfusion services, and the American Red Cross explained quarantine release errors, discussed the causes, and described possible ways to decrease those errors in blood establishments in the future. QREs occur when collected blood is found to be contaminated, expired, or otherwise unsuitable for donation, yet through a range of errors, blood or blood product was inadvertently released to a patient anyway. This type of error can result in injury and even death to the recipient of improperly labeled or handled blood. The main cause of QREs has been determined to be human error. The workshop's effort was aimed at exploring possible strategies to address QREs and making blood collection and distribution safer for patients everywhere.

Applications Opening Soon for the 2012 Audi Gerstein Platelet Disorder Scholarship

To commemorate Audi Gerstein, who was deeply committed to the PDSA Discussion Board forum and involved in education of others, PDSA created a scholarship in her honor to award to those suffering from platelet disorders. The first $1,000 scholarship was awarded in 2009.

Applications for the Gerstein Scholarship Open March 16th

The Audi Gerstein Scholarship Program provides financial assistance to senior high school students, college students, or adults interested in continuing education who are suffering from ITP or a similar inherited or non-inherited platelet disorder.

Applications are accepted from March 16th through April 16th. Winners will be announced on May 16th.
In addition to the $1,000 Scholarship, several students will be given $100 book awards. Winners will be announced on our PDSA Website, in our quarterly newsletter and at the Annual ITP Conference. Last year's winner, Dean Freundlich, was able to attend PDSA's Annual ITP Conference in Boston, MA.

For more information and instructions go to: *http://www.pdsa.org/resources/scholarship-program.html*
You will see the previous winners and the application for 2012. For additional questions, feel free to contact the home office at toll-free (877) 528-3538.

You Can Contribute

To make a donation to the Audi Gerstein Scholarship Program visit *www.pdsa.org* and click on 'Support the Scholarship Program.' PDSA is a 501(c)3 organization. All donations to the Scholarship fund are tax deductible.

Kids Korner

By Ayla Charness, ITP Patient and Children's Miracle Network 2011 Colorado Champion

My name is Ayla Charness, I am 10½ years old and was diagnosed with ITP seven years ago. I know that there are a lot of hard things that I have had to go through with ITP, but I have also gotten to do some really cool things. This year I was named the 2011 Colorado Champion for Children's Miracle Network Hospitals (CMNH). CMNH raises money for a lot of different Children's Hospitals including my hospital, Children's Hospital Colorado.

I was nominated by the Foundation of my hospital to help CMNH in raising money to help the hospital. There is only one person picked per state. Throughout the year I got to go to a lot of events, tell my story, and help in getting fundraising and support for Children's Hospital. I love going around, sharing my story and helping the hospital that has helped me so much. It is also fun meeting all the great people that I have met. I have spoken at golf tournaments and kick-off meetings for Costco, Wal-Mart, and Sam's Club. I also got to go around during the Dairy Queen Miracle Treat Day (one of my favorites).

The most exciting part of the year was the Champions Trip that we took in October. We went on a trip to Orlando, Florida and Washington, DC with the champions from every state. It was fun meeting new friends and being around kids that know what it is like to deal with some kind of medical condition (I was the only one with ITP).

Ayla and her family at the White House (back: Audrey and Jay Charness; front: Ayla and sister, Amanda)

Our whole family went and we got to meet a lot of people who do fundraisers and give money to help us kids. It was fun to share my story and help to explain how important it is to get help for kids like me. I also got to go on stage at an awards gala with Meredith Vieira. She was super-nice and we had a fun time talking on stage together.

I also got to visit a place that I have wanted to see for a long time, Harry Potter World at Universal Studios. I LOVE Harry Potter, and it was so much fun to go and see what it was like in the books and movie. 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. This year was fun, and it was really neat to be able to help out other kids going through stuff like I am.

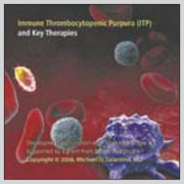
To hear Ayla talking with Meredith Viera, visit PDSA's homepage: *http://www.pdsa.org*

> "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."
> – Ayla

Ayla Charness, Children' s Miracle Network 2011 Colorado Champion, receives her medal from the President of Ace Hardware

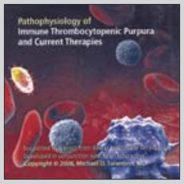
PDSA Offers ITP DVDS!

Two animated, color DVDs about ITP, produced by PDSA Medical Advisor Dr. Michael Tarantino, are now available:*



"ITP and Key Therapies"
(approx. 13 minutes)
$20, plus shipping and handling

- Designed for individuals with ITP and parents of children with ITP.
- Describes what is known and unknown about how ITP starts, how platelets are destroyed and what causes ITP to continue.
- Covers how the drugs used to treat ITP work.



"Pathophysiology of ITP and Current Therapies"
(approx. 13 minutes)
$30, plus shipping and handling

- Designed for health care providers who care for ITP patients.
- Describes the mechanisms of autoantibody production, platelet destruction and altered platelet production in ITP.
- Describes the mechanism of action of common ITP therapies.

To order these DVDs, visit our Web site at *www.pdsa.org* and click on the shopping cart icon that says "Platelet Store." On the left side of that screen, choose the "Products" bar. Then click on the DVD(s) you want and click on "Order" to place your order. For telephone orders, call PDSA toll-free at (877) 528-3538.

*Proceeds from the sale of these DVDs will be donated to PDSA and other groups that serve the ITP community. These DVDs were developed in conjunction with Siren Interactive, supported by a grant from Baxter Healthcare Corp.

ITP in Adults: Q& A with Dr. Bussel

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low platelet count to prevent clotting. Low platelets alone often do not prevent this kind of clotting. If you have a tendency to clot too much then you may well need to take a blood thinner indefinitely and this puts a little more stress on your platelet count, i.e. for it to be good.

There is a question about ITP and MGUS (monoclonal gammopathy of undetermined significance).

I think ITP can be linked to anything that makes immunity disordered but MGUS usually does not. If either the ITP or the MGUS needed treatment, potentially we would suggest the steroid and rituximab combination because that would help with the MGUS and help with the ITP as well.

As far as we know there are no ethnic groups that are particularly predisposed to ITP nor any in which it does not occur at all.

It is possible that it is less frequent in African Americans but it is equally possible that that is because they do not reveal bruises and petechiae as easily as a function of skin color. There are a number of not common diseases that are linked with ITP such as low antibody levels, hypogammaglobulinemia, or CVID (Common Variable Immunodeficiency). Women, in general, are more disposed to autoimmune disease than men and this may be a function of relatively increased levels of estrogen or of fetal cells in the maternal circulation although the latter is less likely.

Question about the U.S. healthcare system being more like socialized healthcare and how this will affect access to treatments.

I don't think anybody knows for sure but my belief is that we will be developing a system more like that in Canada and Europe where there are sort of treatment algorithms to follow and there will be less ability to choose multiple different paths, i.e. you will have to have failed splenectomy before you could use a thrombopoietic agent. However, there will always be exceptions and hopefully this will stimulate more clinical trials that directly compare different treatments, an area that is sadly lacking.

Next question is about stem cell research and ITP.

I am not aware that there is research specifically in stem cells in regard to ITP. There is some work with so-called mesenchymal stem cells because they are thought to be immunosuppressive and there are two small trials in which they have been used as a treatment of ITP with some success in very preliminary studies.

Finally, there is a question asking if you had ITP what direction would you take to manage your platelet count and try to secure a remission.

In past discussions among the leading physicians in the ITP community, approximately half would do a splenectomy if their original steroid treatment failed and they required continued treatment. Some people might prefer to try a different curative approach using rituximab (Rituxan®). Other people might say, "well, if I could just have a good platelet count on a thrombopoietic agent then maybe I will get better over time." Obviously one focuses on these three therapies but there are many other therapies as well.

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Highlights of 'ITP in Children: Q&A'

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rare) that after MMR vaccine children can develop ITP related to that vaccine. Usually this has a good prognosis (future course and outcome) and they do get better. Certainly there is concern about platelets dropping again on the next MMR vaccination. If you've had your first MMR vaccination and it comes time for the second vaccination, you could have your physician measure titers to see if you still have good antibody titers from the first immunization. If so, you could defer the MMR immunization to later in life. It's always a risk/benefit analysis because for instance measles is still around; we had an outbreak a couple years ago. Measles has the potential to be a bad viral infection but the risk of having ITP gets worse if you catch measles.

If you don't have an active titer against measles and won't have protection from the virus and there's measles in the community, the risk/benefit assessment probably favors getting the vaccination. There is no guarantee that your platelets will not drop with it a little, but getting the measles would be worse.

DR. TARANTINO: In the past, it was thought that the 'bad actor' in the MMR vaccine was the 'R' rubella. At one time you could get these as three separate vaccines — measles, mumps, and rubella. You could see about getting immunized for the measles and mumps only and not the rubella. I haven't heard much about rubella outbreaks but there have been numerous measles outbreaks.

Q: Are there guidelines for getting immunizations after having IVIg? Our hematology doctor won't let us get a vaccine for my daughter within six months of IVIg or if her platelet count is less than 30,000 (fear of hematoma at injection site). For flu vaccine, her doctor prefers she get the live nasal vaccine. Your opinions?

A: DR. TARANTINO: My opinions are based in another bleeding disorder we take care of — hemophilia. We have guidelines and logistics for handling vaccines in someone who has a bleeding disorder. If there is a subcutaneous version of the vaccine available we give that instead of intra-muscular. We put cold treatment to the area after the vaccine is given. As for the 30,000 count cutoff for getting the vaccine, I think you could debate that.

As far as timing vaccines after immune globulin (IVIg), you want the vaccine to do what it's intended to do, which is stimulate antibody production and memory immunity to the germ you're trying to prevent infection with.

DR. GEDDIS: For live vaccines like MMR there is some chance the live virus in the vaccine might inactivate the live virus antibodies before they have provoked the response in the immune system. Six months is a general guideline, not necessarily a hard and fast rule.

Treatment

Q: Regarding a child on clinical trial from Amgen for Nplate® who is able to self-inject at home, why is that different for adults and children who are not in the clinical trial? They have to go in weekly to clinic and have that done. Wondering if you know. I may have to ask Amgen.

A: DR. TARANTINO: The reasons probably go beyond just the logistics that go into that. That's part of the purview of FDA approval for medication. How you store it, package it, how it's advertised, and how it's administered, all is under jurisdiction of the FDA to approve or not approve. In Phase III trials in adults, even in stable dose, for reliable folks we couldn't get injections allowed at home. There could be some ramifications for home-administered drug vs. clinic injected drug. Lots of issues go into the decision and monitoring program for drugs like Nplate and Promacta.

Q: For a child who has chronic ITP with very low (5,000 – 7,000) platelets in whom no other treatments work, which is better — low dose prednisone 5–10 mg or Nplate® for ongoing long-term treatment?

A: DR. GEDDIS: This can be difficult in a child with chronic thrombocytopenia and you can't estimate how long it's going to go on. For as many kids as we have in this situation, we don't treat them all the same because there are lots of other issues that play into what choice you might make. As a long-term strategy people get nervous about using prednisone. Possibly in a small dose you might not get significant side effects but over time side effects related to osteoporosis may be a factor. If you are on prednisone for a long time, this is something that is being monitored to some degree. An advantage of prednisone is it can be taken at home so you don't have to go to the doctor's office each week.

For a patient who lives three hours from the hospital, with limited transportation, coming weekly for an Nplate® injection is just not an option. Also Nplate® is a newer option. The problem with children is that we don't have a lot of data yet in children. There was one small study run by Amgen that's been completed. Hopefully another bigger study is opening soon. If we use it in children, it's basically with the knowledge we're using it "off label". There is a chance the insurance company might not approve it if it's off label. It's very expensive and if it's not an approved indication, that is within their right. I think some monitoring for side effects that we don't know to expect is reasonable because we don't have a lot of experience with this in children. It's hard to say that one is better than the other.

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DR. TARANTINO: We shouldn't underestimate long-term growth and bone density issues that could happen with long-term low dose prednisone. Also other disorders use delivery of steroids (i.e., inhaled steroids for asthma) where we see linear growth changes even with those drugs. A couple of ITP studies showed that the more steroids used the more bone density problems you have and the more it affects the linear height growth. The philosophy of using the least amount or least toxic medication that gives the desired effect on platelets is the way to go. The playing field is changing and every year or two we have additional players on the field. We need studies to do post marketing surveillance to look into these more difficult questions. Prednisone has been around for 60+ years. Some of these older 'grandfathered in' drugs we don't think of doing studies on.

DR. GEDDIS: It's good to get off steroids if you can. There's not a right answer that fits every single patient.

Q: Would you explain what Nplate® or Promacta does?

A: DR. GEDDIS: You have a natural hormone in your body that drives growth of megakaryocytes in your bone marrow that make platelets and it's called thrombopoietin. Most people are familiar with erythropoietin, which makes red cells so thrombopoietin drives the production of megakaryocytes. Nplate® works to stimulate the receptor for that growth factor that same way your natural thrombopoietin does. Promacta works on the same principle.

Q: Are there any supplements you suggest to help with ITP?

A: DR. GEDDIS: Vitamin C helps blood vessel integrity. It is considered very safe. Also, arnica can be used topically for bruises. Some just have good luck with ice and compression.

DR. TARANTINO: A few of our bleeding disorder folks take glucosamine and chondroitin for joint health. However, we found chondroitin (and also fish oils) caused easier bleeding. We tell them not to take chondroitin now and think it should be avoided if you have ITP. Vitamin K helps you produce blood-clotting factors. But more isn't better. In studies it has not been shown to stop bleeding.

> "A couple of ITP studies showed that the more steroids are used the more bone density problems you have and the more it affects the linear height growth. The philosophy of using the least amount or least toxic medication that gives the desired effect on platelets is the way to go."
> – Dr. Michael Tarantino

A Different View

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not have any problems with ITP during the pregnancies. Currently, I try to eat as much organic food as I can afford; also, whole foods.

I am so glad to see that *ITP People* has become a nonprofit organization — the Platelet Disorder Support Association. It is very much needed! Your Web site is also wonderful! Kind Regards, *Stephanie B.*

If you have an unusual success story to share, we'd like to hear it. Send your letters to A Different View, PDSA, 133 Rollins Ave., Suite 5, Rockville, MD 20852, or via e-mail to pdsa@pdsa.org. *Letters may be edited for length and clarity.*

> "Vitamin C helps blood vessel integrity. It is considered very safe. Also, arnica can be used topically for bruises."
> – Dr. Amy Geddis

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