Meet Jerry!
One of the Lucky Ones

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It is with profound sadness that I share the news of the passing of a true ITP Champion. Kathryn West, advocacy director of Amgen Oncology, lost her three-year battle with colorectal cancer on December 9, 2018. I’ve known Kathryn for more than 10 years. She worked with Joan Young, PDSA founder, before I became involved with PDSA. Kathryn was instrumental in the growth of PDSA, making sure that Amgen supported advocacy programs like this newsletter, the PDSA website and annual conference, and most importantly, supporting and educating patients and caregivers through their journey with ITP. When a patient would contact the PDSA office with issues related to Nplate, all I had to do was call Kathryn and she would follow-up immediately, ensuring that patients had access to or could afford the treatment.

Once a nurse, always a nurse. Maybe that is why caring for patients and patient communities was so important to Kathryn. Prior to joining Amgen in the Spring of 2000 as the Clinical Oncology Specialist Director where she led the nursing team in educating nurses and physicians about Amgen’s cancer drugs, Kathryn worked as an Oncology Certified Nurse at the University of North Carolina-Chapel Hill, George Washington University Medical Center, Long Beach Miller Children’s Hospital and UCLA Medical Center. In 2005 she became Amgen’s Advocacy Director.

But it wasn’t just the ITP community and PDSA that Kathryn supported. After Kathryn’s passing, Amgen shared the following comments with me: “For nearly 15 years, she worked tirelessly to initiate, develop, and maintain strong, valuable relationships with advocacy groups across the oncology community. Kathryn worked closely with multiple functions across Amgen, to both develop advocacy engagement strategies, and to leverage her relationships with the advocacy community to meet the needs of cancer patients. Her name was synonymous with the oncology advocacy community. She ensured the patient voice is heard in everything we do in Amgen Oncology.”

Kathryn played a pivotal role in the launch and subsequent success of Breakaway from Cancer and was instrumental in attracting actor Patrick Dempsey (Gray’s Anatomy) as an ambassador for the program, elevating the awareness and impact of the event. Kathryn always put patients first and many survivors involved in Breakaway from Cancer maintained longtime friendships with her.

Kathryn had a way of making you feel special and it was always genuine. Each year at the American Society of Hematology annual meeting when the PDSA team would meet with the Amgen team, Kathryn would open the meeting by saying that the PDSA-Amgen relationship is the model for how a patient advocacy organization and a pharmaceutical company can partner together to truly benefit patients and make a difference in their lives. Even when Amgen team members changed over the years, Kathryn was always the glue.

Kathryn was a force of nature, always professional, but easy-going, warm and funny. She had the best laugh and the biggest smile. She will be missed by all who knew her and were touched by her compassion and fierce passion advocating on behalf of patients with cancer and ITP.

Caroline Kruse, President & CEO
Platelet Disorder Support Association
Preliminary Study Examines Platelet Force and Function as Stronger Indication of Major Bleeding Risk Than Platelet Count in ITP Patients

Deciding when and how to treat ITP patients remains difficult since there is no universally available biomarker or diagnostic test that identifies which patients are at risk for major bleeding. This preliminary study examined a new way of quantifying a measure of platelet function by analyzing individual platelet contraction force. When a platelet displayed decreased contractility, this indicated that the platelets also had impaired platelet function. In agreement with previous research, this study found that impaired platelet function, and not low platelet count, correlated with bleeding in ITP patients. However, this study is still preliminary and needs to be expanded to address whether lower degrees of platelet force correlate with a higher risk of major bleeding, or if patients who naturally have decreased platelet force are just more susceptible to bleeding.


Can Thrombopoietin Levels Predict ITP Patient Response to Treatment with Eltrombopag and Romiplostim?

“Thrombopoietin” (TPO) is the hematologic hormone which is the primary driver of megakaryocyte and platelet production. Patients with ITP generally have near normal TPO levels despite the very low platelet counts.

Both Eltrombopag and Romiplostim are thrombopoietin-receptor agonists (TPO-RAs) used to treat ITP patients. However, there currently is no way to predict if a patient will respond to a specific treatment. This retrospective analysis of ITP patients with baseline TPO levels before treatment with TPO-RAs found that TPO levels display an inverse relationship to response. Patients with lower levels of TPO tended to have an improved chance and larger magnitude of response. At normal TPO levels, Eltrombopag and Romiplostim both have the same likelihood of response. Patients with slightly elevated TPO levels displayed reduced overall probability of response, with Romiplostim having a higher probability of response than Eltrombopag. Patients with high levels of TPO experienced the lowest probability of response from either drug.

This finding parallels previous studies of anemia and erythropoietin (EPO, the hormone that stimulates red cell production) in which pre-treatment EPO levels of > 500 resulted in no response to administration of EPO. A difference however, is that TPO levels may be
Berberine May Offer ITP Patients Suffering from Corticosteroid Resistance Induced by Gut Microbiota Imbalance a New Option for Therapy

Determining a therapy option for ITP patients with corticosteroid resistance has always been a challenging endeavor. Even though extensive research has increased researchers’ understanding of ITP through the discovery of association of bacteria (i.e. Helicobacter Pylori), with thrombocytopenia, no evidence has been found to suggest gut microbiota (the number and types of bacteria in the intestine) are involved in the development of ITP. However, regulating the microbiota has the potential to improve metabolic disorders and allow additional treatment options to be utilized.

In this study, both healthy and ITP patient samples were treated with Berberine, a drug isolated from a Chinese herb to treat diarrhea, to examine if Berberine can alter gut microbiota and thus remedy steroid resistance. The study identified a few strains of bacteria in the gut microbiome that were present at higher levels in ITP patients, and could therefore be the most promising target for treatment.

The treatment of this imbalance in ITP patient samples with Berberine resulted in the partial normalization of gut microorganisms, allowing for the corticosteroid resistance to be corrected. These findings suggest that gut microbiota imbalance may play a role in the development of corticosteroid resistance and therefore makes Berberine a potentially important new therapy for ITP patients.


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The ITP Natural History Study Patient Registry: Preliminary Findings on the Immune Thrombocytopenia Patient Experience

Alexandra Kruse1, Caroline Kruse1, Michele P. Lambert, MD, MSTR2
Platelet Disorder Support Association1
Children’s Hospital of Philadelphia2
Prepared for The American Society of Hematology Annual Meeting 2018

Background
Although significant advances have been made over the past 10 years in the treatment of Immune Thrombocytopenia (ITP), challenges remain in addressing the burden of disease and unmet needs of patients. In rare diseases especially, natural history studies and patient registries are crucial in establishing baseline information and identifying patient-reported outcomes.

Aims
The registry collects data on the natural progression of ITP and characterizes the ITP population as a whole. This preliminary analysis seeks to provide an abridged overview of registry findings.

Methods
The ITP Registry enrolled 843 patients, 742 completed the consent process. Patients completed a set of surveys on demographics, medical and diagnostic data, treatments, and quality of life, with 172 total questions for adults and 141 for children. Of 742 consented patients, 475 (64%) completed >1 surveys. 307 patients completed all surveys.

Results
Patients were 90.3% caucasian and 76.4% female. 86.5% live in the United States. 69.3% of patients were formally diagnosed with ITP <1 year of experiencing symptoms of petechiae, purpura, or mucosal bleeding (range 1-42 years). Average age at diagnosis was 32 years (0-72), although average current age for registry patients is 38 (0-100). Average duration of disease is 12 ½ years, (0-69). An average of 4 (1-10) diagnostic tests are performed to confirm diagnosis. Only 9 patients were diagnosed with another disorder in addition to their ITP.

329 patients who completed the Treatment survey received a total of 1,008 ITP treatments (average 3; range 1-14), almost half of patients were treated with >3 different treatments over the course of their disease. 46/329 patients (14%) received >6 treatments, double the average number of treatments. Almost half (45%) currently receive treatment, but this does not take into consideration whether patients are in remission.

285 (86.6%) patients received steroids. 137 (41.6%) received IV/G. Almost 1/3 received rituximab (31.9%). 121 (36.8%) were treated with thrombopoietic agents; patients also received anti-d, antibiotics, decadron, rituximab, or another treatment for their ITP. 23.7% had undergone splenectomy.

Every patient visited a physician at least once in the past year. ITP patients visit their physicians on average 7 times/year, 42.6% of patients consult their doctor >10 times/year. 64% of patients were hospitalized because of their ITP. Of these patients, 39.8% had been hospitalized within the past year; this may include in-patient treatments.

Most of the adult patients who completed the quality of life (QoL) surveys felt their QoL is good; 1/5 said poor or fair. During the past month, 1/4 patients claimed their overall health was poor or fair, 2/3 said good or very good, 10% said excellent. 62% of patients rate their mental health as good or very good. 82% felt bothered by emotional problems such as feeling anxious, depressed, or irritable in the past week. 64% of patients felt anxious in the past week. Over half of patients report feelings of depression.

A similar trend to mental health was seen in patients’ physical health: 65% said their physical health was good or very good. However, 90% said pain interferes with their QoL. 88% experienced fatigue that week due to their ITP.

38 parents completed the QoL survey on behalf of their child, although not all questions were answered by each respondent. 16/19 parents said their child’s overall health was good or very good. 63% of children were bothered by emotional problems. 29/38 parents said their child feels nervous about their ITP. A majority of children got tired easily due to their ITP; 27/38 children were sometimes, often or always tired. Less than half (15/38) experienced pain from their ITP in the last week, with 6/15 children rating their pain as “greater than 5” on a scale of 1-10 (10= worst pain). 22/38 parents say their child has been physically able to do the activities they enjoy most with no trouble.

Discussion
We focused on general questions across surveys, especially on topics most important to ITP patients. Completion of surveys was hindered by the time and effort needed to answer survey questions. In the future, we hope that completion of the remaining surveys will continue, helping us to examine differences in disease experience across sub-populations. This overview will assist the ITP community with the development of recommendations for standards of care, assist researchers studying the pathophysiology of ITP and interventional outcomes, and support the design of clinical trials for new treatments.
Pediatric ITP: Is it Different from Adult ITP?

By Jenny M. Despotovic, DO

Immune Thrombocytopenia (ITP) has historically been thought to occur in two distinct forms: childhood ITP and adult ITP. This is due to the presumption that childhood ITP is often a mild disease that resolves on its own, while ITP in adults tends to be more chronic and difficult to treat. Some research data exist to justify a different approach to the diagnosis and treatment of ITP in young children and older adults, but ITP in older children, adolescents and younger adults may be more similar than previously thought.

There are clear differences in standard clinical practices and guideline recommendations for the management of childhood and adult ITP. Many of these differences are based on the knowledge of the natural history of ITP in children compared to adults. Adults are less likely to experience remission compared to children, and more often will develop chronic ITP. About two-thirds of adults diagnosed with ITP develop chronic disease, while the majority of children resolve spontaneously, regardless of treatment. Adults are also thought to be more likely to have serious or life-threatening bleeding and have other chronic diseases that can increase the risk of bleeding or other complications. Diabetes, gastrointestinal disorders, high blood pressure and thyroid disease are common conditions found much more often in adults with ITP compared to children. Adults are also more likely to be taking medications that increase the risk of bleeding, such as “blood thinners” like warfarin, non-steroidal anti-inflammatory (NSAID) agents including aspirin and ibuprofen, and anti-platelet therapies. All these medications can increase risk of bleeding, especially in a patient who also has low platelets.

Because of these factors, a hematologist is likely to do more testing to look for an underlying cause of an adult’s ITP and also more likely to treat an adult with newly diagnosed ITP and a low platelet count (generally under 30), regardless of whether there is bleeding or not. IVIG, anti-D immune globulin, and steroid therapy are often used for initial treatment. These same agents are the front-line treatments recommended for a child with ITP if they have bleeding or are at increased risk of bleeding.

More recent research suggests there are also many similarities between adult and pediatric ITP. Late remissions (resolution of ITP more than a year after diagnosis) can happen in adults, although less frequently than in children. Because adults are usually treated upfront, there is less data available on what natural course the ITP would have taken without treatment. When children are treated with front line therapies for bleeding, they are as likely to respond as adults. When patients continue to have bleeding, bleeding risk, or poor quality of life after a front-line treatment, both adults and children may be candidates for second-line treatments.

Second-line treatments, such as rituximab, thrombopoietin receptor agonists (TPO-RA), splenectomy and others, are used in both adults and children, with similar response rates. The choice of second-line treatment depends on many factors and should be made by the patient, family and treatment team together after weighing the risks and benefits of different approaches. Future research will help hematologists understand ITP biology better, including differences between pediatric and adult ITP, and will hopefully lead to more targeted treatment approaches for everyone affected by ITP.

Dr. Jenny Despotovic, Director, Immune Hematology Program at Texas Children’s Hospital and a member of ITP Consortium of North America (ICON), presents the program “Pediatric ITP: Is it Different from Adult ITP” at ASH 2018.

THANK YOU TO OUR SPONSOR
RETIRED, NOT WITHDRAWN

At 78 years young, this former teacher continues to enlighten and touch the human spirit.

By Nancy Potthast
Jerry Jones considers herself one of the “lucky ones.” As a retired high school science teacher whose classroom was “connected” in 1995, Jerry mastered two skills essential to patient advocacy: identifying the problem and gathering information. Jerry knew that scientific studies are designed to answer specific questions on how to prevent, diagnose, or treat diseases and are critical factors in improving methods of health care. She also knew she had a global network of information and communication services at her fingertips and by entering a few select key words she could unleash a knowledgebase packed with the power to overcome ITP.

In November 2010, Jerry had some testing done when she happened to visit a health fair at the local hospital and the results revealed a 64,000 platelet count. Already scheduled to see her family physician in December, she brought the results with her. Concerned with the results, he checked her platelet count the day of her appointment and found that her count had dropped to 54,000. Jerry recalled how he was swift to point out that he didn’t feel that she had cancer but felt she should be seen by a specialist. “I’m sending you to see a hematologist and you are going to see the word ‘oncology’ on the door, but I don’t want you to worry. This is who you need to see,” he said as he reassured Jerry that he didn’t think it was cancer.

Because of her age and continuous drop in platelet count (Jerry’s platelet count was at 44,000 by January), the hematologist felt she should have a bone marrow biopsy to rule out MDS (myelodysplastic syndromes). When the test came back negative, he diagnosed her with ITP and immediately started her on 60 mg of prednisone. “I went home and took the first dose and that evening I found myself wide awake at 4 am with my brain in turmoil and going every which way. I thought to myself, ‘Why…what have I done differently over the past several months that may have caused this?’” As Jerry recounted the months leading up to her diagnosis, she remembered that in October she was given the H1N1 vaccine (flu shot). She remembered hearing about the Vaccine Injury Compensation Program on a radio program in 2009 and began to do her research into both the vaccine and the program. When Jerry saw thrombocytopenia listed in the full prescribing information, she decided to submit a petition to the U.S. Court of Federal Claims and was granted compensation. “I want to point out that I am not anti-vaccine – we would shut this country down without them, but I am pro-Vaccine Injury Compensation Program. As patients, we need to educate ourselves, and then communicate with our physicians,” Jerry said.

“I wasn’t sleeping those first three weeks and I’m one of the lucky ones who knew how to search the internet. One fine hour, in between cleaning while that prednisone had me awake, I sat down at the computer and was finding all kinds of stuff. I knew about reliable websites and PDSA popped up pretty quick and I joined almost immediately. I also found the International Consensus Report on ITP and I knew that since people from PDSA were involved it must be good and I read all 40 pages of it! After I read it, it gave me peace because it was clear that my hematologist knew what he was doing because he was following those guidelines,” Jerry said confidently.

“My hematologist has been my security blanket, I mean honestly, I don’t know what I would have done without that man,” she continued gratefully. “I know they don’t normally start treatment right away, but mine did. I think he saw the fear in this old woman’s face and said, ‘I need to do something and help her.’” she said with a laugh. “It’s changed my life drastically. I don’t know what I would have done. He didn’t want to jump into a splenectomy, so he tried the dex (dexamethasone) and it worked. I took the last pill in 2012 and have been in normal numbers ever since, but ITP is always in the back of my mind – I know the shoe can always drop,” she said.

Jerry also expressed gratitude for her family physician who also kept a close watch on her overall health. In 2008, Jerry joined and successfully completed a hospital weight loss program in which she shed nearly 100 pounds. Not only did Jerry beat her battle with obesity, she also overcame diabetes and attributes healthy eating and regular exercise as the means to an end of an unhealthy lifestyle. “My A1C did rise to 8 when I started on the prednisone and I hadn’t been on any medication for my diabetes since the weight loss. I don’t know what I would have done without my family doctor who monitored that as well,” said Jerry.

Although she’s enjoying remission, Jerry keeps all issues of The Platelet News since she became a member in 2010. She makes notes on the cover about any new research, treatments or findings and uses them as references. “I made note of fatigue on the cover of an issue from 2011, yet there are still so many doctors who don’t acknowledge that it’s a symptom,” she exclaimed. “I’m always educating myself with the newsletter and website and have reams of paper of printed information I keep in a binder for myself. When I’m online and see what some people say their doctors tell them…well, I know a lot more than their doctors do, unfortunately,” she continued with a giggle.

In addition to her personal ITP library, Jerry sites the ITP Conference as one of her key learning tools. “After attending four conferences, I realized that the presenters are the top in their field – they are more focused on ITP and really know it. My hematologist is great, but he sees lots of other patients with other problems. He’s not focused on ITP and that’s why PDSA’s resources are so important to me,” she said.

PDSA Members may recognize Jerry from her advocacy work in the PDSA Closed Facebook Group, several other Facebook groups, in other online forums and at ITP Conference – Jerry shared her ITP journey as part of the patient panel at ITP Conference 2018. “ITP has no
Jerry Jones (back right) with the patient panel at ITP Conference 2018 in Cleveland, OH.

Jerry noted how drastically life has changed since the passing of her husband in November 2017 and how she now attends doctor visits alone but feels blessed to have her two sons and four grandchildren. In addition to championing the cause for ITP, Jerry keeps busy in her garden where she tends to her favorite flower – the purple coneflower – and even tilled the ground last August to plant winter greens. She travels when she can, spends precious moments with her children and grandchildren and when asked how her family feels about her advocacy work, Jerry simply replied, “It’s not too often you receive compliments from your adult children, but PDSA has afforded me those compliments when they see what it’s about.”

Wife, mother, grandmother, educator, advocate – a winning combination in the fight against ITP and a priceless ally in the All-Star lineup of ITP Awareness Champions. We’re lucky to have you on our team, Jerry.

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The PDSA College 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 6th through April 14th. Winners will be notified by May 31st. The first place winner will be given a $1,500 scholarship, second place will be awarded a $750 scholarship and three students will receive $250 book awards.

Winners will be announced in our quarterly newsletter and at the annual ITP Conference. The $1,500 winner will also be given two (2) complimentary conference registrations to attend this year’s ITP Conference taking place in Washington, DC, July 26-28.

For more information and instructions go to: https://www.pdsa.org/scholarship.html. You will see the previous winners and the application for 2019. For additional questions, feel free to contact the home office toll-free at (877) 528-3538.

HOW YOU CAN HELP INCREASE PDSA’S COLLEGE SCHOLARSHIP FUND

You can make a donation to the PDSA College Scholarship Program at the following website link: https://www.pdsa.org/scholarship-donation.html. PDSA is a 501(c)(3) organization. All donations to the Scholarship Fund are tax deductible.

Over the past few years, some of our award winners have attended our ITP Conference. It’s been a wonderful way of connecting with those involved with the PDSA Program. We hope to see more of you this year.

The key to unlocking better outcomes for people with ITP.

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PLATELET DISORDER SUPPORT ASSOCIATION
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“ITP Registry”

immune thrombocytopenia

patients LIVE with it.
practitioners attempt to MANAGE it.
researchers aim to DEFEAT it.

TOGETHER, WE CAN BEAT IT.

William Keegan McCollum
2018 $1,500 Scholarship Award Winner
Eldorado, TX – Texas A&M University Kingsville

“I would like to thank PDSA once again for your support in college. In my first semester at Texas A&M University Kingsville I learned as much out of the classroom as in class. I learned the advice my parents gave me was true – early is on time, 8 a.m. classes won’t kill you, and don’t skip class. Not skipping class paid off with a higher chemistry grade than I expected. Those of us who came to class were given extra points. As a side note, my platelets are the highest they have ever been since this ITP journey started. My last count was close to 100.”
ITP Treatments Overview: Avatrombopag

By James B. Bussel, MD

The November 2018 issue of the British Journal of Haematology had two recent articles on avatrombopag. One described basic pharmacokinetics in normal volunteers (Kuter & Allen, 2018) and patients with immune thrombocytopenia (ITP). The second reports a phase III trial in ITP (Jurczak et al, 2018). Given that avatrombopag looks effective and safe, the question arises, do we need another thrombopoietic agent?

There is no question that eltrombopag and romiplostim, the thrombopoietin (TPO) receptor agonists available in the United States and Europe, have made a major impact on the management of patients with thrombocytopenia. While these agents have been best studied and first licensed in ITP, they have also had major impacts on other conditions, such as severe aplastic anemia, inherited thrombocytopenias, myelodysplastic syndrome and, recently, chemotherapy-induced thrombocytopenia. The efficacy, safety, and also the tolerability of both agents have been more than acceptable; however, limitations to the use of both agents exist. For romiplostim, it is the need to receive an injection weekly and the potential difficulty in drawing up the exact intended dose. In the United States, romiplostim is still not licensed for patients to do this for themselves although self-treatment at home is licensed in Europe (and probably will be soon in the US). For eltrombopag, the main issue is the dietary limitations. To a certain extent, a person on eltrombopag has to structure their eating around how to manage to take daily eltrombopag. It requires a very empty stomach (no food 2 hours before and after taking eltrombopag, and no calcium (dairy) or iron for 4 hours before and after eating). This usually means not having dairy at dinner, not eating after dinner and then taking eltrombopag at bedtime.

Avatrombopag is similar to eltrombopag in its mechanism of binding to the TPO-receptor in the transmembrane domain and being available orally. This means it does not bind to the TPO receptor at the place where your body's own thrombopoietin itself (and romiplostim) bind which may at least in part explain known patient response differences between romiplostim and eltrombopag. The dietary restrictions of eltrombopag are based on its chelation (binding to) calcium and iron among other cations; when it binds, eltrombopag is inactivated. Avatrombopag is not a chelator and therefore can not only be taken daily by mouth but also does not have dietary restrictions. As reported initially in 2014 and in the phase III study in the British Journal of Haematology, avatrombopag would appear to be similar in efficacy and safety to eltrombopag and romiplostim. In the phase II study I reported on in 2014, and the current study (Jurczak et al, 2018), the efficacy was high. The current study identified four thromboembolic/cardiovascular events in just over 40 patients. This was not seen to this extent in the phase II study and therefore may have occurred because of small numbers; further trials or post-marketing surveillance would be useful to assess this more carefully.

Avatrombopag was recently licensed in the US for procedures in patients with liver disease based on a large randomized placebo-controlled trial. Procedures were not restricted to liver biopsies but included any procedure e.g. dental work. In this 400+ patient study, avatrombopag was effective and safe at high doses but treatment duration was limited to 5 or so days.

Development of avatrombopag has been complicated by its ownership having changed hands so that its development was under the direction of five different pharmaceutical companies at different times in its history. Perhaps as a result, long-term studies are not available despite the initial trial of avatrombopag in ITP having started more than eight years ago. Publications of trial results have been delayed for the same reason. Patients received avatrombopag for six months in the extension of the 2014 study and also for a number of months in the phase III study. In all other efficacy and safety respects, avatrombopag appears comparable to eltrombopag and romiplostim given the much greater volume of data available with these two well-known and widely-used TPO agents.

In development of avatrombopag and evaluation of its safety, there is one other “hiccup” of note. After the phase II trial, Eisai (then owning the rights to avatrombopag) initiated a phase III study; the US Food and Drug Administration (FDA) required a high level of monitoring, including gastroscopy, such that the study was closed for poor accrual. This concern was raised because of rodent studies in which there was a high rate of gastric abnormalities. Subsequently, gastrin and other gastric hormone levels were monitored in the phase III trial and published separately in an abstract submitted to the American Society of Hematology (ASH) 2018 annual meeting. These levels were generally normal, did not increase during the phase III studies, and no laboratory abnormalities were seen. The absence of evidence of issues in humans appears to reflect major differences between rodent and human stomachs and thus to not be of any clinical significance.

In summary, the available data supports avatrombopag as effective, safe and tolerable, as discussed above and based on the cited publications. As with all newer agents, further monitoring and assessments are required, including the treatment of more patients for longer periods of time. If neither the gastric issues nor the risk of thromboembolic events proves to be of concern, avatrombopag may have greater tolerability compared to eltrombopag and romiplostim.
Congratulations to PDSA Medical Advisor James Bussel, MD who was invited to present at the 40th anniversary celebration of the King Faisal Prize, known as the Arab Nobel Prize, at Alfaisal University in Riyadh, Saudi Arabia.

Pioneers in Medicine: PDSA Medical Advisor James Bussel, MD

Dr. James Bussel presenting his lecture “Fetal and Neonatal Alloimmune Thrombocytopenia” at the “Pioneers in Medicine” series at Alfaisal University in Riyadh, Saudi Arabia.

Anonymous
Cathy and Raul Aldama
Susan and John Atkinson
Emily Auterson
Andrew Avrick
Karen and Adam Avrick
Cindy and J. Philip Ayliff
Kenda and Brian Bamesberger
Dai Barbour
Mary and James Benvenuto
Amita and Ranjive Bhalla
Kristen Blackburn
Marisa Braverman
Brendan Cameron
Audrey and Jay Charness
Charlotte Cunningham-Rundles, MD and James Bussel, MD
Druanne Davies
Leilani de Castro
Jenny Despotovic, DO
Linda and Kris Dorasami
Michelle and Dan Eppinghoff
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Karen and David Imig
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Mary John and Mannminder (Mindy) Combow
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Jody and Jon Shy
Gerald Spaniol
Julie Stires
Dana and Thomas Stotz
Michael Tarantino, MD
Kristen and Steve Tomczak
Kelly Torres
Lois Umhoefer
Elizabeth and Robert Welch
Joseph Winter
The Winter Family
Molly Wirtz
Cheri and Derek Zimmerman
Joyce and Dale Zimmerman

The Circle of HOPE

CIRCLE OF HOPE
OCTOBER – DECEMBER, 2018

Anonymous
Cathy and Raul Aldama
Susan and John Atkinson
Emily Auterson
Andrew Avrick
Karen and Adam Avrick
Cindy and J. Philip Ayliff
Kenda and Brian Bamesberger
Dai Barbour
Mary and James Benvenuto
Amita and Ranjive Bhalla
Kristen Blackburn
Marisa Braverman
Brendan Cameron
Audrey and Jay Charness
Charlotte Cunningham-Rundles, MD and James Bussel, MD
Druanne Davies
Leilani de Castro
Jenny Despotovic, DO
Linda and Kris Dorasami
Michelle and Dan Eppinghoff
Kim and Jim Everett
Robert Feiner
Allison and Keith Flowers
Susan Frank
Gretchen and Stephen Frickx
Jan and Steve Gardner
Terry Gersheimer, MD
Jen and Benjamin Grimes
Marilyn and Tim Groves
Brenda and Kevin Gubrud
Kim and Rodney Hall
Mira and Jim Hauesser
Aandrea and Billy Hays
Kristin Henrikson and Jon Brandt
Patricia and Bennett Henrikson
Noelle and Mat Heyman
Melissa Hilsabeck
Elizabeth and Jerry Hoogendoorn
Madeline and John Hromyak
Sherrill Hudson
Hazel and Steve Huey
Renea and Tellys Hunter
Karen and David Imig
Emily James
Mary John and Mannminder (Mindy) Combow
Amanda Johnson
Joan and Richard Jordan
Genevieve Kilianek
Louise Kittel Mason
Jennifer and Bob Krueger
Caroline and Ken Kruse
Irene and David Kuter, MD, DPhil
Laura and Mike Ledin
Angie and Alan Levitt
David Lihani
Jenn and Andy Lindal
For the Love of Gracie
Mary Lou Lyons
Marci Mayhew
Katharine McCleary
The McGuirl Family
Deborah Melisop Lyons
Irma and Daniel Miles
Kim and Bobby Moore
Stephanie and Mike Moran
Louann Murtagh
Patricia and C. Ben Nelson
Yazdi Parekh
Susan and Dale Paynter
Jonathan Peischl
Jeanne and Dan Pinnell
Jacqueline and Bruce Prescott
Laura and Neal Prescott
Meredith Prescott
Barbara and Peter Pruitt Jr.
Shirley and Peter Pruitt Sr.
Patricia Pulley
Angela Racoosin
Linda and Steve Rauh
Kawanda Reid
Virginia Rennie
Steven Rodgers
Karen Rosenbaum
Jazmin Ross
Trish and Paul Santaromana
Lisa Scott
Hayley and Nathan Shimaneck
Jody and Jon Shy
Gerald Spaniol
Julie Stires
Dana and Thomas Stotz
Michael Tarantino, MD
Kristen and Steve Tomczak
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The Winter Family
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IN APPRECIATION

The following individuals were active in the CIRCLE OF HOPE between October 1 and December 31, 2018. Circle of Hope members donate or raise $1,000.00 or more within a calendar year and serve as PDSAs' philanthropic leaders.
Save the Date
PDSA’s 19th Annual ITP Conference in Washington, DC

This year, PDSA will host its 19th annual update on immune thrombocytopenia (ITP) for patients, caregivers and the medical community in Washington, DC July 26-28. This year’s patient conference will take place at the Fairmont Washington, DC, Georgetown. Each year the ITP conference provides opportunities to hear the latest information about ITP, meet others who are coping and living with ITP and receive answers to your medical questions. You will also have the opportunity to ask your questions to PDSA’s Medical Advisors, who are some of the most experienced ITP doctors in the world. You don’t want to miss out on this tremendous opportunity to hear and talk with these world-renowned experts.

A highlight to the weekend will be the Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting on Friday, July 26, where representatives from the FDA will be on-hand to get patient feedback on current ITP treatments and future drugs in development. You don’t want to miss this important meeting, which will begin at 11:00 AM on Friday, July 26 and run until 4:00 PM. Lunch will be provided and a patient mixer will follow the close of the meeting. (see article on page 15 for more detailed information about the EL-PFDD meeting.)

In addition to the educational program and social events, our conference will feature several small group sessions to give you an opportunity to get to know other patients and caregivers in an intimate environment. We will also offer programs for children at our Kids Kamp for children ages 5-12. Like last year, this year’s conference will provide a separate track for teens and young adults.

Program for This Year’s Conference Include:

Check the PDSA website as more information becomes available, including speakers for this year’s conference.
If you plan to stay at the **Fairmont Washington, DC, Georgetown**, please reserve your room as soon as possible to receive our special conference rate of $149 a night (king or queen/queen), plus tax. **This rate is for 2 adults or a family of 4 with children under age 18. Triple and quad occupancy rate is $179.00 per night.** This special PDSA rate is also available for conference attendees three days before and three days after the conference. This special rate applies to reservations that are made by July 3, 2019, as long as rooms at the hotel are available. We encourage you to make your hotel reservation early to ensure room availability. Reservations can be made online here: [https://bit.ly/2AAYiym](https://bit.ly/2AAYiym) or by calling 202-439-2400 and referencing the group code is **Platelet Disorder Support Association**.

**Scholarships**

Partial scholarships to attend the ITP Conference are available. Please see the Registration Form for more information. You can return your completed registration form, along with your letter describing your diagnosis, your financial need and the benefit you hope to derive from attending the conference by June 28, 2019. Information can be returned via email at bfoster@pdsa.org, by fax at (844) 270-1277 or via mail to PDSA, 8751 Brecksville Road, Suite 150, Cleveland, OH 44141.

**Cancellation Policy**

If you need to cancel your registration for the conference, you must submit your request to cancel in writing prior to July 3, 2019. All fees less a $50 administrative charge will be refunded if a written request is received before the July 3rd deadline. **After July 3, 2019 no refunds will be issued.**

**Questions?**

If you have any questions or require assistance while completing the registration form, please contact Jody Shy at the PDSA office at (440) 746-9003 or (877) 528-3538 or via email at jshy@pdsa.org.
PDSA to Host Externally-Led PFDD Meeting

By Caroline Kruse

ITP Conference 2019, taking place July 26-28 in our nation’s capital, will give patients and caregivers a rare opportunity to have their voices heard. On the first day of the conference, Friday, July 26, PDSA is organizing an externally-led patient-focused drug development meeting (EL-PFDD). As North America’s leading organization dedicated to empowering ITP patients, PDSA has been approved by the U.S. Food and Drug Administration (FDA) to lead this workshop to enhance the understanding of ITP and the patient experience by regulators, researchers, clinicians and industry.

The purpose of PFDD meetings is to hear directly from patients, their families, caregivers and patient advocates. The FDA has conducted over 25 disease-specific PFDD meetings to more systematically obtain the patient perspective on specific diseases and their treatments. The FDA recognizes that there are many more disease areas that can be addressed beyond the PFDD meetings planned and conducted by FDA, so they are giving patient advocacy organizations the opportunity to host their own PFDD meetings, with input and guidance from FDA. After submitting a letter of intent to FDA, PDSA was honored to be selected to organize and host an EL-PFDD as part of our annual ITP conference.

According to FDA, “The patient perspective is critical in helping FDA understand the context in which regulatory decisions are made for new drugs. PFDD meetings give FDA and other key stakeholders, including medical product developers, health care providers, and federal partners, an important opportunity to hear directly from patients, their families, caregivers, and patient advocates about the symptoms that matter most to them, the impact the disease has on patients’ daily lives, and patients’ experiences with currently available treatments. This input can inform FDA’s decisions and oversight both during drug development and during our review of a marketing application.”

What can you expect from an externally-led PFDD meeting?

If you have attended any of PDSA’s past conferences, you know we always end the conference on Sunday with a patient panel, where patients share their personal journey with ITP. Always insightful and inspiring, if not often heartbreaking, patients learn a tremendous amount about their disease from other patients and caregivers. Over the years, we have had patients say to us “Why don’t you have these patient panels earlier in the conference so that the doctors can hear what it is like to live with ITP?” Well, think of the EL-PFDD program as a larger patient panel session. We will have two patient panels of 4-6 patients/caregivers each who will talk about the symptoms and burden of living with ITP and the impact of treatments and their side effects. PFDD meetings are also facilitated large group discussions where all patients and caregivers in the room will have a chance to share what is like to live with their condition; discuss the daily impact of ITP, tell stories to highlight their unmet needs, and describe the shortcomings and advantages of current therapies and treatments. As experts in what it is like to live with their condition, ITP patients and caregivers are uniquely positioned to inform the understanding of the therapeutic context for drug development and evaluation.

The EL-PFDD will be a half-day meeting and run from 11am-4pm on Friday, July 26 (note that the conference will start earlier on Friday than in past years and that there will not be a Friday evening program). Registration will start at 9am and lunch will be served. Following the EL-PFDD meeting, PDSA will host a patient mixer from 4-5pm with appetizers and non-alcoholic beverages. With a number of new ITP drugs in the pipeline, we hope you can join us for this rare opportunity to have your voice be heard and truly make an impact on the understanding of the unmet medical needs and quality of life issues that matter most to ITP patients.
WHEN IN ROME, SUPPORT ITP PATIENTS!

Milwaukee, WI Group Takes Support on the Road – Globally!

Talk about six degrees of separation! The following email correspondence between PDSA President & CEO Caroline Kruse, Milwaukee, WI Support Group Facilitator Kim Everett and PDSA Member Patricia Conry from the U.S. and U.K. shows that no matter where your travels take you, ITP is not as rare as most people think!

From: Patricia Conry
Sent: Tuesday, December 18, 2018 11:35 AM
To: Caroline Kruse; Kim Everett
Subject: U.K.

Dear Caroline,

I enjoyed seeing you at the U.K. conference in Chester recently. Now that I am living 70% of my time in the U.K. I decided to start a small support group for the W. Sussex area, meetings to be held in Chichester, which is the closest town to where I live.

When living in Port Washington, Wisconsin, I attended many of our support group sessions. Kim Everett mainly ran those sessions, so I am familiar with the format. With guidance from Merv Morgan (Chief Executive, ITP Support Association U.K.), I realize that there is much ground work to accomplish first. I am presently in the USA for a few weeks and upon my return to U.K., hope to work on getting a group together.

If you are interested I will keep in touch with you. I hope to come to the next conference in Washington, DC in July 2019.

Yours sincerely,
Patricia Conry

From: Caroline Kruse
Sent: Tuesday, December 18, 2018 11:35 AM
To: Patricia Conry; Kim Everett
Subject: U.K.

Dear Patricia,

It was lovely to see you in Chester as well. I am so delighted to hear that PDSA and one of our very first support group facilitators, Kim Everett, were of help to you. You have a great role model in Kim! PDSA has a strong relationship with the ITP Support Association and I shared with Mervyn PDSA’s New Facilitator Kit that Nancy (PDSA Director of Marketing) created for our support groups in the U.S. This is their first foray into creating local ITP support groups in the U.K.

Please stay in contact and let us know how things are going. PDSA also oversees the globalitp.org website and we can include any of your meeting notices or photos/overview of meetings.

Happy Holidays and hope to see you in Washington, DC!

Kind regards,
Caroline

From: Kim Everett
Sent: Tuesday, December 18, 2018 3:20 PM
To: Caroline Kruse; Patricia Conry
Subject: Re: U.K.

Greetings Caroline and Patricia,

We’re currently in Florida visiting family for the holidays, so typing on my cell phone and will keep it brief and hopefully free from typos.

Patricia, we will miss you, but happy you’re finding home in the U.K. and are interested in starting a support group. Yay for you!

Interestingly, while in Italy for a three week holiday, we ran into a very nice woman from the U.K. while on a walking tour in Naples. We hit it off right away and she joined Jim and me for lunch. Long story short, turns out her brother has ITP. Go figure! Can’t even recall how it came up, but imagine her surprise when I told her I also have ITP. Then I told her I was on the board of PDSA, and that there was a support organization in the U.K. She was thrilled, as she was worried about her brother. Another interesting coincidence, he had a stem cell transplant for ITP. Upon finding out I did too, I thought she would cry to learn all these coincidences. And to see I was happy, well and traveling the world, set her spirit soaring.

I provided all the links to PDSA and Global sites, U.K. site, annual conference, etc. Then we ate pizza overlooking the Mediterranean and shared a few bottles of wine. Lol.

I have her contact information and will connect with her and inform her of your desire to start a support group in the U.K. I do believe her brother might be near Sussex, but will confirm with her upon our return after Christmas. She is near Dover, but I suspect would be interested in a support group, in support of her brother.

We’ll miss you in Wisconsin, but looks like you’ve landed home and will be kept busy supporting ITP patients in U.K. They’re going to love you and you’re going to be a fantastic support group leader. If there’s anything I can do to assist, don’t hesitate to email me.

Warmest regards and happy holidays.
Kim

Milwaukee, WI support group facilitators Kim and Jim Everett showcase their fresh pasta made during a cooking class while visiting Rome, Italy.
PATIENT-FOCUSED MANAGEMENT OF ITP: Hematologist Viewpoints from the European Hematology Association Congress

By Alexandra Kruse

Many ITP patients wonder which treatment might give them the best chance at achieving remission. At the 23rd Congress of the European Hematology Association in Stockholm, PDSA Medical Advisor Drew Provan, MD, of Queen Mary University of London, chaired the Amgen symposium. “Patient-Focused Management of ITP — interactive case studies and unanswered questions” to help hematologists understand the best way to individualize treatment strategies for their ITP patients.

This article is the last of a three-part series on therapy individualization for ITP patients presented at the summit, and will cover "Remission in ITP: an Achievable Goal?“ By Bertrand Godeau, MD, PhD, of University Hospital Henrietta Mordor, in Paris. ITP is considered chronic after a year following diagnosis of low platelet counts and becomes chronic in 60% of patients diagnosed. The goal of treatment for physicians is to procure a stable and safe platelet count, rather than a “cure,” or sustained platelet counts above 100,000. Physicians consider a platelet count above 30,000 to be safe, unless the patient has a lifestyle with a higher risk of trauma, must take modifying hemostasis agents such as aspirin, has other comorbidities, or presents with a poor health-related quality of life and suffers from fatigue. In some cases, the ITP will resolve but then return months or years later; many physicians choose to use the word “remission” as a temporary diminution in the severity of disease, instead of “cure” for this reason.

For first-line treatments, steroids such as prednisone and dexamethasone do not modify the natural history of ITP; long-term, dexamethasone does not improve a durable platelet response any more than standard-dose (long-term) prednisone.

The response rate of Rituximab is 60% in adults, but many patients relapse; after five years, only 20-30% of patients continue to see safe platelet counts. Dr. Godeau said this rate could be improved through a better selection of candidates for Rituximab, but there are currently no predictive factors of a sustained response. A second option is to repeat Rituximab infusion in patients who initially respond, or combine Rituximab with Dexamethasone or Cyclosporine, to obtain better long-term results.

A sustained response has been demonstrated after treatment with the TPO agents (romiplostim (Nplate®) and eltrombopag (Promacta®/Revolade®), with a 10-30% chance of obtaining a stable platelet count off-therapy. In case of relapse after stopping treatment, physicians are able to re-treat their patients with the same or a different TPO agent and still see a response in platelet count elevation. In fact, if a response is not achieved on one of the TPO agents, there is a 50% chance of obtaining a response on the other, as each of the therapy molecules bind to different sites on the TPO-receptor in our bodies. Patients concerned about toxicity and side effects after restarting the agents, literature shows that the frequency or severity of adverse events (typically headaches) does not increase over successive cycles of therapy. In combining therapies, Promacta and Dexamethasone show a consistent response at 6 months in 75% of patients vs. Promacta alone; Rituximab and recombinant human TPO (rhTPO) (a type of TPO agonist that closely mimics your naturally-produced thrombopoietin, not yet approved in the US) significantly increase the response rate (but do not show a beneficial impact on long-term response); and treatment with TPO at maximal dose combined with immunosuppressive therapy demonstrates a 70% response rate in patients. This supports the idea that individualized and combined therapies may be a good option for patients seeking remission.

A popular option for remission, 66% of patients achieve a complete response following splenectomy. However, in 15% of these cases the platelet counts plateau and the patient is considered to have relapsed. One significant issue to consider is the risk of infection (commonly pneumococcal or sepsis) and risk of thrombosis (clotting not just immediately after surgery, but observed years post-operatively). Therefore, better indicators beyond age, sex, and sequestration pattern (where the platelets are destroyed) are needed.

Immunosuppressants are typically only used for patients refractory (non-responsive) to all other therapies. One of the more popular immunosuppressants, Mycophenolate Mofetil (MMF), demonstrates an overall response rate of 52%, and according to Dr. Godeau, should thereby be considered a second-line therapy alongside Rituximab and the TPO agents. There is currently not enough data on remission rates from immunosuppressants to make a validated statement on whether they alter the natural course of ITP.

In conclusion, steroids do not improve chances of remission, Rituximab and the TPO agents show remission rates typically when combined with other therapies, more data is required to show remission from immunosuppressive therapies, splenectomy causes remission in a majority of patients, but there is a need for a safer and better way to select good candidates for surgical intervention.
EMPOWERING KIDS WITH ITP – EN ESPAÑOL!

Announcing the latest version of acclaimed publications introducing young children to the world of ITP!

Available online and in print. Visit https://pdsa.org/translated-publications for the complete list of languages available and visit www.globalITP.org to connect with patient advocates around the world!

PDSA. Your family resource for living with ITP.

Join us at one of our 2019 walk locations as we Pump It Up For Platelets!

April 27  London, ON Canada
May 18    Ames, IA
September 7 Beloit, WI
September 14 St. Louis, MO
September 21 Chicago, IL
September 28 Orange County, CA
October 12 Cleveland, OH
TBD        Cranberry Twp, PA
TBD        Houston, TX
TBD        Lawrenceburg, IN

Now is the time to start planning your 2019 Pump It Up for Platelets! event. Contact PDSA’s Programs and Events Manager, Jody Shy at jshy@pdsa.org if you would like to organize a walk/run in your community.

Special thanks to our Silver Sponsors:
PDSA Fundraising News

Thank you to our 2018 Awareness Champions who continue to inspire, share and educate the world about ITP! Do you or someone you know run, walk, cycle or participate in other community fitness events? We would love to add your name to our list of Awareness Champions. Contact PDSA’s Programs and Events Manager, Jody Shy at jshy@pdsa.org for more information and to set up your personal fundraising page.

<table>
<thead>
<tr>
<th>Event</th>
<th>Organizer(s)</th>
<th>Location</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>IGI Chicago Style Fundraiser</td>
<td>Dana Stotz</td>
<td>Chicago, IL</td>
<td>$1,031.35</td>
</tr>
<tr>
<td>Facebook Fundraisers</td>
<td>Multiple</td>
<td>N/A</td>
<td>$26,425.15 to date</td>
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<tr>
<td>Pennies for Platelets</td>
<td>Kelly Doherty</td>
<td>Hockessin, DE</td>
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<tr>
<td>For the Love of Gracie Walk</td>
<td>Jenn &amp; Andy Lindal</td>
<td>Everett, WA</td>
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<td>Tri-Beta Bio Honor Society</td>
<td>Jennifer Roberts, PhD</td>
<td>Sandwich, IL</td>
<td>$700.00</td>
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<tr>
<td>Lounsberry Hollow Middle School</td>
<td>Kristie Lyons</td>
<td>Vernon, NJ</td>
<td>$145.00</td>
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<tr>
<td>In Honor of Piper Saige Gyory</td>
<td>Corrie Gyory</td>
<td>Culpeper, VA</td>
<td>$625.00</td>
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<tr>
<td>Children’s Rainbow Day School</td>
<td>Lynn Clow</td>
<td>Goulds, FL</td>
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<td>Braverman Fundraiser</td>
<td>Marisa Braverman</td>
<td>Melville, NY</td>
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<td>Lagree Fundraisers</td>
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<td>Explorers Academy</td>
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<td>In Loving Memory of Barbara Ranken</td>
<td>Karrissa Ranken</td>
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<td>Sunset Shores Fundraiser</td>
<td>Kristen Blackburn &amp; Marci Mayhew</td>
<td>Clare, MI</td>
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<td>Freed Fundraiser</td>
<td>Marcia Freed</td>
<td>Rockton, IL</td>
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<td>In Memory of Luca</td>
<td>Jennifer DiRaimo</td>
<td>London, ON</td>
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<td>Pedal for Platelets/Cycling for Steve</td>
<td>Wanda Gregory</td>
<td>Tucson, AZ</td>
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<td>Molly’s ITP Awareness Marathon</td>
<td>Molly Wirtz</td>
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<td>Rylan Our Hero</td>
<td>Kathy Oaks</td>
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<td>Diane Mille</td>
<td>N. Kingstown, RI</td>
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<td>Raising Cains Fundraiser</td>
<td>Talon Crist</td>
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<td>Archer &amp; Greine</td>
<td>Stephanie Zane, Esq.</td>
<td>Haddonfield, NJ</td>
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<td>Bleeding &amp; Clotting Disorders Institute</td>
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<td>Diamond Credit Union</td>
<td>John Faust</td>
<td>Pottstown, PA</td>
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<td>Hally Fundraiser</td>
<td>Maureen Halley</td>
<td>Basking Ridge, NJ</td>
<td>$200.00</td>
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</tbody>
</table>

For a complete list of fundraising events, visit https://pdsa.org/give-back/host-fundraiser.html

PDSA IS PROUD

to be accredited by the Better Business Bureau and to be recognized as a Gold level participant by GuideStar, a standing only 5% of registered charities achieve and a testament to our operating transparency.
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, President and CEO, at (877) 528-3538 toll free or by e-mail, ckruse@pdsa.org.

Awareness Champions (L-R) Lilly Stotz, ITP Warrior Torie Stotz and Mackenzie Stotz manning the booth at the IGI Chicago Style gymnastics event in Chicago on February 9-11, 2018. Torie Stotz is now a gymnast for the University of Illinois, competing at the D1 level. Keep up the great work, Torie!


GIVING MADE EASY THROUGH FACEBOOK

In 2018, Facebook Friends and Followers raised over $40,000 in support of a cause they care about - PDSA programs and research! Facebook Birthday Fundraisers make giving easy and no fees means 100% of contributions are donated to PDSA.

Empower ITP Patients
Donate Your Birthday
www.facebook.com/plateletdisorder
What Our Friends Are Saying on Facebook

Hello ITP family my name is James David Jr I will be 4 months old on the 13th I was diagnosed with ITP at 2 months old. I just wanted to say keep fighting guys we got this❤️

Sometimes you’ve just got to laugh ITP and wrinkles on the forehead don’t mix...!!! My little one looked like she had horns on holiday 😱

Hello!

My daughter was diagnosed with ITP in April, 2017. She had a count of 2. It took a few months, but thankfully, she ended up being an acute case and has fully recovered.

This group was a very important source of support for me during that time. I just wanted to say thank you and offer hope and support, especially to parents with newly diagnosed kiddos. 😁

This gives me hope❤️...how long did it take for your daughter to become stable

4w Like Reply Comment

Write a comment...
TOGETHER, we can take on ITP

ITP CAN BE A CHALLENGING CONDITION

Whether you’ve just been diagnosed or have been living with immune thrombocytopenia (ITP) for some time, the disease can often feel overwhelming. We designed MyITPLife.com to be a resource for you and your loved ones whenever you may need it.

Find answers, links, and much more at MyITPLife.com today:

- ITP BASICS
- MANAGING ITP
- DOWNLOADABLE TOOLS
- PATIENT STORIES
- AND MORE...

LET’S MOVE FORWARD
MyITPLife.com
The Hidden Strength of a Snowflake

By Cyma Shapiro

Reprinted with permission, Matthews Beacon 2018

When the curtain goes up for the “Nutcracker,” danced by the Matthews Ballet and Dance, at the McDowell Community Center, one dancer in the group will be happy to be alive, well, and again dancing in this year’s production.

Matthews resident, Caroline Kramb, has been dancing with this group since she was four years old. She is now 15 and has taken on such roles as Angel, the lead – Clara, Chinese, Ginger Child, Waltz of the Flowers, Candy Cane, Spanish, Gold Angels, Party Girl and Soldier.

This year, as in previous years, she will exude the joy and passion that dancing invokes in many. “Caroline is a dedicated student with a passion for dance,” said dance studio Program Director Amanda Sheppard. “She loves performing onstage, and is always a joy to watch.” This year, she will dance the part of “Snowflake.”

Also, as she has in previous years, Caroline will be grateful for this opportunity. However, when she performs, many in the audience will be unaware of her ongoing serious medical struggles, her courageous approach to her illness, and her willingness to share her story in an effort to fundamentally help others.

Approximately 2 1/2 years ago, at the age of 12, Caroline developed a severe rash and became extremely tired. What her family thought would be a common trip to the doctor turned out to be much more serious. Her bloodwork showed that she had a rare blood disorder called idiopathic thrombocytopenic purpura (ITP). Symptoms include low platelets and chronic bleeding. “We were in utter shock,” said her mother, Brooke.

Upon diagnosis, Caroline was rushed to Levine’s Children’s Hospital for a short stay and subsequent 18 months of treatments including infusions and heavy doses of steroids – protocols that left her feeling weak, tired and sick.

“It was hard for me with dancing, just going to school and just living my normal life,” said Caroline. “I had to push myself much harder than the other girls. (Although I knew) I am just as healthy and strong as the other girls… (I had an) autoimmune disorder. I looked good, but you couldn’t tell I had to work harder.”

At points, she missed days of school after eight-hour treatments needed every six to eight weeks – “all of that was very emotional,” she said. She was also banned from (her) competitive swimming and all activities for which there might be a propensity for getting hurt (should she fall, hurt or bruise herself, it could cause internal bleeding). Both she and her mother, Brooke, said she felt “embarrassed” to not be able to do things that other kids could do, and longed to just “be like others.”

With that in mind, she ardently chose to continue her weekly dance lessons and maintain her participation in the annual Nutcracker productions.

“I just get really excited for the Nutcracker,” said Caroline. “I’ve had dance in my life longer than anything else I’ve ever done. Being able to (dance in) the Nutcracker every year (gives me) a sense of assurance. When I was a lot sicker, a lot weaker, I still had that event to look forward to, to participate in.”

To her dance teachers and fellow dancers, keeping this routine was paramount to keeping her spirits up. “I know that dance is (Caroline’s) ‘happy place’ and her way to escape her illness,” said Sheppard. “She shows such amazing resilience for someone so young. I think dance has given her the strength to never give up but to always remain determined and focused.”

According to Brooke, the Nutcracker and Caroline’s continued participation in dance lessons (two hours/week for dance classes; up to five hours a week during Nutcracker rehearsals), as well as her family, friends and faith all “helped her cope as well as thrive.”
During her second stay in the hospital, in the chemo-bays, she saw young kids playing but realized that older children had nothing to do with themselves during this stressful and difficult time. The “lightbulb” went off. Caroline said to her mother, “For my birthday, I want to invite my friends, but I want them to give donations so we can make our ‘bags.’”

The “activity bags,” as they were called, were intended to be filled with “things to do.” To date, she has made and delivered close to 100 bags and also made several hundred bracelets to pay for the bags, all of which are donated to children/teens also undergoing treatment at Levine Children’s Hospital.

Caroline has also become an ITP activist. Two years ago, she started her own Instagram page called “World Free of ITP,” which she created to “express my feelings…I would talk about when I had to go to the hospital and my thoughts about the journey – to (help others) understand how real this disorder is.”

Last summer, she applied for and received a scholarship to attend an ITP conference in Cleveland, Ohio, where she met with other teens struggling with the same issue, and those hematologists who care for them.

“Before I was sick, I was the winiest and weakest person out there,” said Caroline. “I’d cry when I got shots. I wouldn’t take pills. But, after going through all that, I honestly didn’t have a choice. I had to push myself to get stronger and get over my fears. I honestly think it happened for a reason…Coming out of being sick, I just knew, ‘I just want to help other people….so they don’t have to go through this.’”

Caroline now wants to be a hematologist. When she turns 16, she has been invited to shadow her lead hematologist at the children’s hospital.

Today, Caroline’s platelets are stable and she is considered in remission (there is no cure for ITP). She remains fixated on the goal of learning more and helping others. “Definitely the way she has reached out to others – she has done this entirely on her own,” said Brooke.

“Because I have ITP, it is like an obligation to know everything; to be informed and understand the doctors because I want to help others,” said Caroline. “I want to help understand even other blood disorders because I want to know how to give back and find other ways to help.”

IN HONOR

We received contributions from October 1, 2018 to December 31, 2018 in Honor of:

Raymond James Blair, Jr.  Addison Claire McLaren
Katie Brand  Rosalia Olson
Emily Calvert  Tyler Scott Paris
Ayla Charness  Meredith J. Prescott
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IN MEMORY

We received contributions from October 1, 2018 to December 31, 2018 in Memory of:

Erik Anderson  Edward Wayne Glover
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If you are considering an honorarium donation, please contact PSDA:

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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. Contact Jody Shy at jshy@pdsa.org or call toll free at 1-877-528-3538. For information on meeting locations, dates, and times please contact the group facilitator.

The contact information in this section is provided as a service EXCLUSIVELY to patients and families. IT IS NOT TO BE USED FOR COMMERCIAL GAIN IN ANY FORM OR FOR ANY OTHER PURPOSE UNLESS STATED IN WRITING FROM PDSA. Interested parties other than patients and families should contact pdsa@pdsa.org for more information.

ITP PARENTS TELECONFERENCE GROUP
Facilitator: Jay Charness, jay@ape-strangerawareness.com or (303) 731-7731

2019 Meeting Dates:
March 6, June 11, September 4, November 12

CANADIAN TELECONFERENCE GROUP - CANADA
Currently looking for a Facilitator

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

2019 Meeting Dates:
January 27, March 31

WATERLOO-WELLINGTON, GREATER TORONTO ONTARIO - CANADA
Facilitator: Dale Paynter, waterwellpdsa@rogers.com or (519) 651-2352

PHOENIX, ARIZONA
Facilitator: Bunnie Stevenson, bunnie145@cox.net or (480) 451-7661

2019 Meeting Dates:
February 2

ROGERS (NORTHWEST), ARKANSAS
Facilitator: Cas Chubinski, chubinski.pdsa@gmail.com or (269) 788-2522

LOS ANGELES (SIMI VALLEY), CALIFORNIA
Facilitators: Nina and Stephanie Schussman, nschussman@hotmail.com or (818) 370-8877

ORANGE COUNTY, CALIFORNIA
Facilitators: Melissa Hilsabeck, Cathy Aldama, Leilani de Castro, & Kelly Torres
ITPhnetworkingOC@gmail.com or (714) 598-7102

2019 Meeting Dates: February 12, May 14, August 6, October 29

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

SACRAMENTO, CALIFORNIA
Facilitators: Dawn and John Phillips, dphil75895@aol.com or (916) 607-1699

2019 Meeting Dates:
January 19, April 27, June 29

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

WASHINGTON, D.C.
Facilitator: Cindy Ayliff, cindyayl@cox.net or (703) 849-0054

MIAMI, FLORIDA
Facilitator: Barbara Pruitt, barbarampruitt@gmail.com; (305) 409-6887

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

THE VILLAGES, FLORIDA
Facilitator: Marcia Freed, blsmlk1@yahoo.com; (815) 978-5740

2019 Meeting Dates: February 25

ATLANTA, GEORGIA
Facilitator: Joan Coppolino, mariettajoanie@yahoo.com or (770) 924-2258

CHICAGO, ILLINOIS
Facilitator: Trish Santaromana, chicagoitpsupport@comcast.net or (630) 292-1485, http://chicagoitpsupport.org

2019 Meeting Dates:
April 13, July 13, November 9

PEORIA, ILLINOIS
Facilitator: Marsha Hurn, marsha@ilbcdi.org or (390) 692-5337

SOUTH COOK COUNTY, ILLINOIS
Facilitators: Barbara & James Jacobs, BARB04ITP@gmail.com or (708) 957-3222

2019 Meeting Dates:
March 23, June 22, September 28, November 23

BALTIMORE, MARYLAND
Facilitators: Doris Galvez, dee32981@aol.com or (443) 815-9167
Lillian Ellinger, lillian.ellinger@yahoo.com or (443) 858-4283

BOSTON, MASSACHUSETTS
Facilitator: Michael Westfort, michael@platelethealth.org or (508) 366-1073 or (508) 930-0309
CLARE, MICHIGAN
Facilitator: Marci Mayhew, MidMIITP@yahoo.com or (989) 418-2740
2019 Meeting Dates: February 10, May 19, July 21, October 20

DETROIT, MICHIGAN
Facilitators: Sharon Cisco and Linda Galka, itpdetroit@yahoo.com or (586) 783-8014

ST. PAUL, MINNESOTA
Facilitator: Joe Winter, ITPnetworkingMN@gmail.com or (651) 792-5277

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

CENTRAL/NORTH NEW JERSEY
Facilitators: Linda McGuirl, Susan Anderson, Marcella Perez njpdsa@gmail.com or (908) 764-1819
2019 Meeting Dates: January 19, March 16, May 18, September 21, November 16

NORTH NEW JERSEY
Facilitators: Dianne Danielle, sonnydeeb@aol.com or (201) 265-8875
Lanie Gastman, lanieg45@aol.com or (201) 592-1181

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

NEW ZEALAND
Facilitator: Wendy Grace Allen, ITPNZ@gmail.com
https://www.facebook.com/ITPNewZealand/
https://www.facebook.com/groups/ITPNZ/

LONG ISLAND, NEW YORK
Facilitator: Claudia Montuori, claudia.montuori@yahoo.com or (631) 563-6567

ROCHESTER, NEW YORK
Facilitator: Robert Monigle, bmonigle@gmail.com or (585) 721-8639

TRIANGLE, NORTH CAROLINA
Facilitators: Donna Goldstein, ds.goldstein@mindspring.com and Emily Goldstein, ebug123@gmail.com or (919) 942-4082

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

CINCINNATI, OHIO
Facilitator: Oliver Markowitz, ITPCincinnati@gmail.com or (920) 284-4677
2019 Meeting Dates: January 27, March 31, May 26, July 28

CLEVELAND, OHIO
Facilitator: Caroline Kruse, ckruse@pdsa.org or (440) 526-0629
2019 Meeting Dates: February 7, May 16, November 14

POWHATAN POINT, OHIO – SOUTHEASTERN OH/WV
Facilitator: Camie Sims, camie1222@gmail.com or (304) 816-2608

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

RHODE ISLAND
Facilitators: Lisa & Steve Sack, Lflsack@gmail.com or (401) 884-5711

CENTRAL SAVANNAH RIVER AREA (AIKEN), SOUTH CAROLINA
Facilitator: Angela Howell, csra.itp@gmail.com or (803) 599-1692

CHATTOOGA, TENNESSEE
Facilitator: Sharon Putnam, sharonputnam@gmail.com or (423) 991-6450

NASHVILLE, TENNESSEE
Facilitator: Charity Hasty Backs, raeoflove@hotmail.com or (615) 473-3372

AMARILLO, TEXAS (PANHANDLE)
Facilitator: Robin Abshire, RABS2183@aol.com or (337) 296-7052

AUSTIN, TEXAS
Facilitator: Kaemarie Nasamram, kaemarien@yahoo.com or (512) 905-5643

DALLAS FORT WORTH, TEXAS
Facilitators: Linda and Kris Dorasami, PDSA.dfw@gmail.com or Linda (817) 727-2351 or Kris (817) 727-2361 and Marsha Inman (817) 247-7271, minmanfw@att.net

HOUSTON, TEXAS
Facilitator: Mark Ciesielski, marktcie@juno.com or (713) 723-1633
2019 Meeting Dates: January 13, March 3, May 19, July 21, September 15, November 10

SALT LAKE CITY, UTAH
Facilitator: Cory Bushman, Cory.Bushman@uhsinc.com or (801) 404-4580

PULASKI, VIRGINIA
Facilitators: Whitney Boyd, weoneshc@msn.com or (540) 230-6712 and Cheryl Boyd, cheryl24301@msn.com or (540) 641-6185

SEATTLE, WASHINGTON
Facilitators: Tammy Fassett, tcfassett@gmail.com or (206) 465-3451 and Taylor White, taylorhwhite2012@aol.com or (253) 250-5873
2019 Meeting Dates: January 27, April 28, July 28, October 27

MILWAUKEE, WISCONSIN
Facilitators: Kim Everett, wipdsa@gmail.com or (920) 717-0839
2019 Meeting Dates: April 27, August 24, November 16

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