

*You are
invited...*



ITP CONFERENCE

JULY 8-10 2016



ORLANDO, FLORIDA

Learn about the most up-to-date ITP information
Talk face-to-face with the world's top ITP doctors
Share experiences with others in the ITP community

Join Us for our 16th national
patient conference at the
Hilton Orlando Bonnet Creek

Find more information at www.pdsa.org

 **PDSA**
PLATELET DISORDER
SUPPORT ASSOCIATION

for People with ITP

Invitation to Participate

PDSA's 16th annual update on immune thrombocytopenia (ITP) for patients, caregivers, and the medical community will take place at the beautiful **Hilton Orlando Bonnet Creek** in Orlando, Florida, July 8-10. Our three-day program is not only an important update on information about immune thrombocytopenia (ITP), but it is also a chance to meet others affected by ITP. You will also have the opportunity to ask your questions to PDSA's medical advisors, 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.

Each year the conference provides opportunities to hear the latest information about ITP, meet others who are coping with ITP, and receive answers to your questions. A highlight to this weekend will be a patient mixer on Friday evening and a special family-oriented party Saturday evening. PDSA realizes how important it is to offer patients and families a respite from dealing with a chronic illness while bringing a little joy and laughter into their lives. In addition to the educational programs and social events, we will have programs for children at our Kid's Kamp for all children ages 5 and up. New this year is a separate track for teens and young adults.

This year's programs include: *The ABC's of ITP: How Much Do You Really Know about This Autoimmune Bleeding Disorder? (take the ITP Jeopardy Challenge!)*, *Children with ITP: Treatments, School Issues & Sports, For Teens Only*, *Treating ITP: Balancing Risk vs. Benefit, For Women and Girls Only: Bleeding Disorders and Reproductive Issues*, *Top Concerns for ITP Patients: From Fatigue to Vaccines*, *Care for the Caregiver*, *Communicating With Your Doctor: What Every ITP Patient Wants Their Doctor to Know*, *Can We Cure ITP? Research that Considers Patient's Needs*, *Feeling Invincible: Teens Living with Chronic Illness*.

We have scheduled time with our exhibitors so you can meet directly with the companies who are providing new treatments and sponsoring clinical trials. We guarantee what you will learn about the nature of ITP, its diagnosis, treatment, and management will make a positive difference in your own or your loved one's health.

I hope you and your family can join us for an informative, educational and inspirational conference this July at the **Hilton Orlando Bonnet Creek** in Orlando, Florida.

MORE INFORMATION

Visit our Web site:

www.pdsa.org

Call toll-free:

1-87-Platelet (1-877-528-3538)

E-mail: **pdsa@pdsa.org**



Caroline Kruse
Executive Director

About the Speakers

DONALD M. ARNOLD, MDCM, MSC, FRCP(C)

Dr. Donald Arnold is an Assistant Professor in the Department of Medicine at McMaster University in Hamilton, Canada and Program Director for the McMaster Transfusion Medicine Residency Program. Dr. Arnold obtained his MD from McGill University and completed training in Internal Medicine at the Jewish General Hospital in Montreal. He then completed Hematology training at McMaster in 2003 and a Fellowship in Transfusion Medicine supported by the Canadian Blood Services and the Canadian Institutes for Health Research (CIHR). He holds a Master's degree in Health Research Methodology from McMaster and is the recipient of a CIHR New Investigator Award. Dr. Arnold is a translational researcher with a focus on immune thrombocytopenia (ITP). He is the lead investigator on several clinical trials in ITP and has developed a program of research that spans clinical studies designed to better understand patient preferences with respect to ITP treatments to basic research on the mechanisms of ITP.

JAMES BUSSEL, MD

Dr. James Bussel is Professor of Pediatrics, Medicine, and Obstetrics at the Weill Medical College of Cornell University in New York City. His training was initiated at Yale, continued at Columbia College of Physicians and Surgeons, then he completed a Pediatric Residency at Cincinnati Children's Hospital, and a Fellowship in Pediatric Hematology/Oncology at the combined Cornell/Memorial Sloan Kettering program. The great majority of Dr. Bussel's publications are centered around diagnosis and especially management of patients with ITP, including children with ITP, adults with ITP, pregnant women with ITP, HIV infected patients with thrombocytopenia, and fetuses affected by autoimmune and alloimmune thrombocytopenia. He has worked with IVIg, IV anti-D, rituximab, and most recently the thrombopoietic agents.

JANE PERNOTTO EHRMAN, M.ED.

Jane Ehrman, owner of Images of Wellness, LLC, is a Mind/Body Medicine Specialist in Cleveland, Ohio, where she maintains a private practice. She works with adults and children on a variety of issues, including: High-risk pregnancy, chronic disease treatment and recovery issues, lifestyle behavior change, pain management, performance anxiety for students, musicians and athletes, stress-related illness and conditions (headaches, irritable bowel, insomnia), and preparation for surgery. Besides her private work, Jane is the Lead Behavioral Health Specialist at the Cleveland Clinic's Center for Lifestyle Medicine, in the Wellness Institute. There, she develops and implements the behavioral and stress management sections of lifestyle wellness programs for people with chronic disease related to lifestyle. Jane has a Master's of Education from Pennsylvania State University, with an emphasis on Mind/Body Medicine and an undergraduate degree in Health Education from Youngstown State University. She completed post-graduate course

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About the Speakers continued

work at Case Western Reserve University and Rainbow Babies and Children's Hospital, Department of Child and Adolescent Behavioral Medicine, Cleveland, OH. Jane trained at The Harvard Mind/Body Medical Institute in Boston, MA, and the Academy for Guided Imagery in Malibu, CA.

AMY GEDDIS, MD, PHD

Dr. Amy Geddis is Associate Clinical Professor of Pediatrics, Seattle Children's Hospital. She specializes in genetics of platelet disorders. She received her MD and PhD from Jefferson Medical College, Thomas Jefferson University in Philadelphia, PA. She completed her Pediatric Residency at Children's Hospital, Pittsburgh, PA and Fellowship in Pediatric Hematology/Oncology at Fred Hutchinson Cancer Research Center, Seattle before moving to UCSD. Dr. Geddis has received numerous academic honors. Her many publications have added to our understanding of the role of thrombopoietin in platelet production and the nature of inherited thrombocytopenias.

TERRY GERNSHEIMER, MD

Dr. Terry Gernsheimer is Professor of Medicine, University of Washington School of Medicine; Medical Director, Platelet Antibody Laboratory, Puget Sound Blood Center, and Director of Transfusion Services, University of Washington Medical Center and Seattle Cancer Care Alliance. She has a medical degree from SUNY, Stony Brook, NY; completed internship and residency in Internal Medicine, New England Deaconess Hospital, Boston, MA and fellowship in Hematology, University of Washington. Research interests include diagnosis, treatment and pathophysiology of autoimmune platelet disorders.

ANDRA JAMES, MD, MPH

Dr. Andra James is an Associate Professor of Obstetrics & Gynecology in the Division of Maternal Fetal Medicine at the Duke University Medical Center in Durham, NC, where she directs the Women's Hemostasis and Thrombosis Clinic. Dr. James graduated from the University of Virginia School of Medicine, trained in Obstetrics and Gynecology at the University of North Carolina, and completed her Fellowship in Maternal-Fetal Medicine at Duke. Her practice, research, and advocacy pertain to reproductive issues among women with hematologic disorders. Dr. James participates or has participated in a number of organizations that serve patients with blood disorders and is currently President of the Foundation for Women and Girls with Blood Disorders.

CRAIG KESSLER, MD

Dr. Craig Kessler, Professor of Medicine and Pathology, is the Director of the Hemophilia and Thrombosis Comprehensive Treatment Center and Director of the Division of Coagulation in the Department of Laboratory Medicine at Georgetown University Medical Center in Washington, DC. His research interests include development and analysis of treatment strategies for

bleeding disorders such as hemophilia, von Willebrand disease, and ITP. Dr. Kessler has also designed and participated in numerous clinical trials to study the pathophysiology and treatment of thrombophilic states, such as venous thromboembolism and cancer. He has written over 250 papers and chapters and is co-editor of a popular authoritative textbook on consultative hemostasis.

DAVID J. KUTER, MD, DPHIL

Dr. David Kuter is Chief of Hematology, Massachusetts General Hospital, Boston, Massachusetts. He earned a research doctorate (DPhil) at Magdalen College of Oxford University and a medical degree at Harvard Medical School. Dr. Kuter is Professor of Medicine at Harvard Medical School. In addition, Dr. Kuter sits on numerous national and international ITP committees and is board certified in Internal Medicine, Hematology, and Medical Oncology. He has dedicated years of effort to researching coagulopathies, anticoagulation, and platelet disorders. In recent years, Dr. Kuter has conducted groundbreaking research into the development of effective thrombopoietic agents.

MICHELE P. LAMBERT, MD, MTR

Dr. Lambert is an Assistant Professor of Clinical Pediatrics at the Children's Hospital of Philadelphia and Medical Director of the Special Coagulation Laboratory at CHOP. She graduated from UMDNJ-New Jersey Medical School (now Rutgers) and completed her pediatric residency at St. Christopher's Hospital for Children followed by a year as Chief Resident. She then moved to the Children's Hospital of Philadelphia where she completed her fellowship in pediatric hematology/oncology. She received her Masters in Translational Medicine in 2001. Her research efforts have focused on understanding the control of platelet production by megakaryocytes (the cells that make platelets) and the ways in which genetics influence platelet function and number in various clinical scenarios including ITP and inherited platelet disorders.

HOWARD A. LIEBMAN, MD

Dr. Howard Liebman is Professor of Medicine and Pathology at the University of Southern California's (USC) Keck School of Medicine, Los Angeles, CA. He serves as Medical Director of the Special Hemostasis Laboratory at USC's Norris Comprehensive Cancer Center and is Director of the fellowship program in hematology. Dr. Liebman received his medical degree from USC and completed his postgraduate training including a residency in internal medicine and fellowships in medical oncology and hematology at Los Angeles County – University of Southern California Medical Center. Dr. Liebman completed a research fellowship at Tufts University – New England Medical Center, Boston, MA and held faculty positions at Tufts University and Boston University, before returning to USC. Dr. Liebman's research interests include clinical management and characterization of haemostatic and thrombotic disorders, management of autoimmune blood disorders and clinical therapy of HIV and AIDS. He has authored or co-authored 85 peer-reviewed publications and 26 reviews and chapters. *(continued on the next page)*

About the Speakers continued

DIANE J. NUGENT, MD

Dr. Diane Nugent is a Clinical Professor, Department of Pediatrics, University of California, Irvine School of Medicine. She currently serves as Chair, Hematology, CHOC Children's Hospital of North Orange County, Orange, CA; Medical Director, Hematology and Blood and Donor Services CHOC Children's; and Division Chief, Hematology, CHOC Children's Specialists. Dr. Nugent is a nationally-recognized expert in pediatric hematology who specializes in blood disorders, bone marrow failure, bleeding and clotting disorders, anemias, and immune deficiencies. She is involved in clinical trials for rare blood disorders and is a principal investigator for regional hemophilia programs. Dr. Nugent has coauthored more than 100 journal articles and book chapters. She chairs review subcommittees at the National Heart Lung and Blood Institute (NHLB) at NIH in hematology. Dr. Nugent also participates in the Pediatric ITP Consortium of North America (ICON), a group of pediatric hematologists dedicated to improving the understanding, treatment, and quality of life (QOL) of pediatric ITP patients.

JOHN W. SEMPLE, PHD

Dr. John Semple received his PhD in Immunology from Queen's University in 1986 and trained as a Post-Doctoral Fellow in the Banting and Best Department of Medical Research of the C.H. Best Institute, University of Toronto from 1986-1990. He joined St. Michael's Hospital in 1990 and is currently the Director of Transfusion Medicine Research of the Toronto Platelet Immunobiology Group and a Professor of papers on platelet immunology. His research activities include several areas including anti-platelet T cell responses in patients with acute and chronic ITP, the analysis of how platelet antigens are recognized by the immune system, and how platelets may act as immune-like cells that are responsible for initiating and perpetuating their own autoimmune demise.

MICHAEL TARANTINO, MD

Dr. Michael Tarantino is a Professor of Pediatrics and Medicine at the University of Illinois College of Medicine-Peoria and Medical Director of the Bleeding & Clotting Disorders Institute. He received a doctoral degree in medicine from the University of Wisconsin School of Medicine in 1987. He completed an internship and residency at the University of Arizona Health Sciences Center and a Fellowship in Pediatric Hematology/Oncology at the University of Wisconsin School of Medicine. Dr. Tarantino first became interested in ITP during his residency in 1988. Since that time he has designed and/or participated in numerous clinical investigations related to ITP and other platelet disorders. He has authored numerous publications relevant to the diagnosis and management of ITP, especially as it occurs in children. He is also active in hemophilia and other bleeding disorders research.

Conference Location



All educational sessions, exhibits, and social events will take place at:

HILTON ORLANDO BONNET CREEK

14100 Bonnet Creek Resort Lane, Orlando, FL 32821

ROOM RESERVATION INFORMATION

All meeting activities will be held at **Hilton Orlando Bonnet Creek**. Set within the 482-acre Bonnet Creek Nature Preserve, this modern 1001-room resort hotel is surrounded by the Walt Disney World Resort®. The Hilton Orlando Bonnet Creek is a Walt Disney World Good Neighbor® Hotel offering a magical resort experience with a three-acre lazy river pool, waterslide, 12 dining options and complimentary transportation to Walt Disney World® Theme Parks and Disney Springs™. Tee off at the 18-hole championship golf course or pamper yourself with a spa treatment at the adjacent Waldorf Astoria® Orlando.

If you plan to stay at **Hilton Orlando Bonnet Creek**, please reserve your room as soon as possible to receive our special conference rate of \$129 a night (king or queen/queen), plus tax. This rate includes complimentary guest room internet and access to the fitness center. 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 **June 15, 2016, 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://aws.passkey.com/event/14485528/owner/9591246/home>

You may also call **1-888-353-2013** and reference the Platelet Disorder Support Association ITP Conference 2016. On-site parking is available for an additional fee.

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Conference Location continued

HOTEL TRANSPORTATION

The Hilton Orlando Bonnet Creek offers a complimentary shuttle to Walt Disney World® theme parks and back. Shuttles run every half hour.

AIRPORT TRANSPORTATION

The Hilton Orlando Bonnet Creek is located 18 miles from the Orlando International Airport (MCO). The following are approximate fees for airport to hotel transportation:

- **Taxi** – approximately \$55 each way.
- **Mears Shuttle** – \$22 each way or \$36 round trip for adults and \$18 each way or \$36 round trip for children.
- **UBER** – \$85-\$108 from airport to hotel, \$30-\$70 from hotel to airport.

HOTEL PARKING

- **Self-parking** – \$15.00 (Garage Parking), discounted for conference guests from \$18.00.
- **Valet** – \$26.00 (Valet Parking)

2016 NATIONAL ITP CONFERENCE SPONSORS

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Gold Sponsor



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Scholarship
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Conference Agenda*

* A separate track for teens and young adults will run Friday and Saturday.

FRIDAY, JULY 8

- | | |
|-----------------|--|
| 3:30PM – 6:00PM | Registration / Exhibits Open |
| 4:00PM – 6:00PM | Canadian Patient Advocacy Meeting |
| 5:00PM – 6:00PM | Patient Mixer |
| 7:00PM – 8:30PM | Concurrent Presentations |
| | <ul style="list-style-type: none">• The ABC's of ITP: How Much Do You Really Know about This Autoimmune Bleeding Disorder? (take the ITP Jeopardy Challenge)• Children with ITP: Treatments, School & Sports• For Teens Only |

SATURDAY, JULY 9

- | | |
|-------------------|---|
| 8:00AM – 9:00AM | Registration / Continental Breakfast / Exhibits Open |
| 9:00AM – 10:00AM | Treating ITP: Balancing Risk vs. Benefit |
| 10:00AM – 10:15AM | Break |
| 10:15AM – 11:30AM | Top Concerns for ITP Patients: From Fatigue to Vaccines |
| 11:30AM – 11:45AM | Break |
| 11:45AM – 12:45PM | Concurrent Presentations |
| | <ul style="list-style-type: none">• For Women and Girls Only: Bleeding Disorders & Reproductive Issues• Care for the Caregiver |
| 12:45PM – 1:45PM | Lunch Break with PDSA Medical Advisors |
| 1:45PM – 2:45PM | Communicating With Your Doctor: What Every ITP Patient Wants Their Doctor to Know |
| 2:45PM – 3:00PM | Break |
| 3:00PM – 4:00PM | Concurrent Presentations |
| | <ul style="list-style-type: none">• ITP in Adults: Q&A• ITP in Children: Q&A |
| 4:00PM – 4:15PM | Break |
| 4:15PM – 5:15PM | Can We Cure ITP? Research that Considers Patients' Needs |
| 5:15PM – 5:30PM | Announcements |
| 5:30PM – 7:00PM | Pre-dinner Break |
| 7:00PM – 8:00PM | Educational Program / Complimentary Dinner |
| 8:00PM – 10:00PM | Saturday Evening Event |

SUNDAY, JULY 10

- | | |
|-------------------|--|
| 8:00AM – 9:30AM | Continental Breakfast |
| | Support Group Facilitators' Breakfast (pre-registration requested) |
| 9:30AM – 10:30AM | Bringing Your Best to Life and Health Challenges |
| 10:30AM – 10:45AM | Break |
| 10:45AM – 11:45AM | Living with ITP: Patients share their stories |
| 11:45AM – 12:00PM | Closing Remarks |

*Agenda and speakers subject to change

Registration Information

SCHOLARSHIPS / Partial scholarships that cover ITP Conference registration for two and your hotel room for 2 nights (Friday and Saturday) are available. Please return your completed registration form, along with a letter describing your diagnosis, your financial need, and the benefit you hope to derive from attending the conference. Information can be returned via email at jshy@pdsa.org, by fax at (844) 270-1277 or via mail to PDSA, 8751 Brecksville Road, Suite 150, Cleveland, OH 44141. The deadline for scholarship applications is May 31, 2016.

Please note: Travel costs are NOT included in the partial scholarship. Due to the limited number of scholarships available, they will be awarded on a first come, first serve basis and preference will be given to first-time conference attendees. You **MUST** be a PDSA member to be eligible for a scholarship.

CANCELLATION POLICY / If you need to cancel your registration for the Conference, you must submit your request to cancel in writing prior to June 15, 2016. All fees less a \$50 administrative charge will be refunded if a written request is received before the June 15th deadline. **After June 15, 2016 no refunds will be issued.**

ADMISSION TO SESSIONS / Upon registration at the conference, all attendees will receive a personalized name badge. These name badges must be worn at all times during the conference sessions and conference meals. Admission to conference activities will be restricted to badge holders.

EXHIBITS / Some of our sponsors will exhibit products and services directly related to ITP. Only vendors who have permission from PDSA will be allowed to distribute materials. Other promotional materials will not be permitted in the meeting halls, registration, or reception area.

CONFERENCE ATTIRE / All sessions are casual attire and will be held in the hotel meeting rooms, which are air-conditioned. However, please remember, everyone has their own personal preferences for temperature and it is often difficult to control temperatures in a hotel setting. It is recommended to bring along a light jacket or sweater to the session rooms. Dress for the Saturday night PDSA Family Fun event is Caribbean casual — so come to celebrate and have fun!

CONFERENCE ETIQUETTE / Please be considerate of others during all educational sessions and turn off all cell phones and pagers or set them to vibrate. Please arrive on time or early for the sessions you plan to attend, allowing time to add extra chairs if necessary.

QUESTIONS? / If you have any questions or require assistance while completing the registration form, please contact Jody Shy at **(440) 746-9003** or **(877) 528-3538** or via email at jshy@pdsa.org.



Registration Form

Mail to: PDSA

8751 Brecksville Road, Suite 150, Cleveland, OH 44141

or fax, with credit card payment, to (844) 270-1277

Full payment is due at time of registration.

(Mr./Ms./Mrs./Dr.) First Name Middle Last Name Suffix [_____] Member ID# filled in by PDSA

Address

City ST or Province ZIP Code Country

Phone (H) Phone (Cell) Email @

Please also include Name, Address, and Phone Number for each additional guest/family member.

☐ I have special dietary needs. Please explain:

☐ I would like to apply for a partial scholarship that will cover my conference registration for two (2) and hotel room for two (2) nights.

**** Registration includes all sessions, receptions, Continental breakfasts on Saturday and Sunday, and Saturday lunch**

If you are not a PDSA member, you can become one for a \$25 Membership fee and then choose the discounted Conference cost under the Member Fee column. As a member you will receive the 28-page quarterly newsletter, *The Platelet News*, can participate in the Name Exchange program and will receive discounted rates for the Annual ITP Conference.

☐ PDSA Membership (\$25, \$50, \$100 or more).....\$ _____

Early Registration: Through June 15, 2016 After June 15, 2016, registration fees will increase.

	MEMBER FEE	NON-MEMBER FEE	
Individual	\$125	\$150	\$ _____
Children ages 5-12	\$50	\$60	\$ _____
Children 4 and under	FREE	FREE	\$ <u>FREE</u>

Registration: One Day Pass (Fri/Sat or Sat/Sun) \$100 Member \$120 Non-Member..... \$ _____

PDSA Circle of Hope Member Registration: 2 complimentary Registrations \$ FREE**

~or~ PDSA Facilitator Registration: 1 complimentary Registration \$ FREE**

☐ I would like to include an additional amount to defray conference expenses.. \$ _____

TOTAL REGISTRATION: \$ _____

Payment Method: ☐ Visa ☐ Master Card ☐ American Express ☐ Discover

Name on Card: _____ Card No.: _____

Exp. Month _____ Year _____ CSC CODE _____ AMT charged: \$ _____

Your CSC Code is the 3 digit code on the back of your MC/V/Discover card or 4 digit code on the front of AMEX

☐ Check or Money Order payable to PDSA (will accept only a US bank check, US funds, no cash)

*DISCLAIMER: I recognize that photographs, video recordings and other media will be taken during the event. I further grant permission to PDSA (PLATELET DISORDER SUPPORT ASSOCIATION) and/or other agents authorized by them to use any photos, recordings and other media or record of this event for any purpose.

**Only a total of 2 complimentary registrations can be redeemed and they are non-transferable.