



# ITP CONFERENCE 2023

*The Premier Patient Event*

July 21-23

Swissôtel, Chicago, IL

## Celebrating PDSA's 25<sup>th</sup> Anniversary!

We invite you to join us for our 23<sup>rd</sup> national patient conference to:

- 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

Find more information at [www.pdsa.org](http://www.pdsa.org)

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# Invitation To Participate



2023 marks PDSA's 25<sup>th</sup> anniversary and our 23<sup>rd</sup> annual ITP Conference. We hope you will join us at the Swissôtel in downtown Chicago, IL, July 21-23, for this in-person event. ITP Conference 2023 is intentionally designed to offer ITP patients, caregivers, clinicians, and industry partners the unmatched opportunity to gather as a community, to reconnect with and learn from one another, and to reap the invaluable benefits of this shared experience.

Described by attendees as life-changing, this premier patient event promises to help you grow in your understanding of ITP, partner more effectively with your care team, and take control of your ITP and your overall health-related quality of life. You'll have the chance to hear from, speak directly with, and have your questions answered by PDSA Medical Advisors, some of the foremost ITP experts in the world. Equally impactful is the opportunity to be among a community of fellow ITP patients who are walking your same journey and who have a shared understanding of what it means to live with this rare disease.

**We have designed a robust and interactive conference agenda, including sessions on:** How Do I Know I Have ITP and What Does That Mean? • The Impact of ITP on Quality of Life • ITP in Adults Q&A • ITP in Seniors • ITP Through the Ages • Living with ITP: Patients share their stories • Rare Bleeding Disorders During Adolescence, Pregnancy, and Menopause • Shared Decision Making: making the right choices in ITP management • Teen Session, for parents of teens • Treatment Strategies and Emerging Therapies for ITP • An Update on Pediatric ITP • What is a Clinical Trial and How Does it Work? • In Sickness and in Health: How Chronic Medical Illness and Rare Diagnoses Impact Families and Couples • The Mind Body Connection: Medical Trauma, Rare Disease, and Strategies for Resilience

Back by popular demand, Inquire & Inspire sessions give patients and caregivers dedicated time to discuss their ITP journeys with one another and to ask questions of PDSA Medical Advisors.

We will also offer age-appropriate programs for our Kids Kamp children, ages 5-12. A separate track for teens and young adults will be facilitated by PDSA Medical Advisor and pediatric hematologist Michael Tarantino, MD, and members of his Bleeding & Clotting Disorders Institute staff.

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 Swissôtel in Chicago, IL. Our 23<sup>rd</sup> annual ITP conference – and PDSA's 25<sup>th</sup> Anniversary – promises to be a weekend of education and inspiration. We look forward to seeing you there!



Caroline Kruse  
President and CEO

## What people enjoyed during ITP Conference 2022:

"The breakout sessions for adults with a doctor or two – very easy conversations and learned a lot."

"Women/girls session provided a safe space to ask sensitive questions."

"Hearing all the doctors and their opinions on different medication/treatments."

"The small groups with doctors because we got to ask specific questions and get feedback on our circumstances."

# Conference Agenda

## FRIDAY, JULY 21

8:00 – 9:00 AM	<b>Hike &amp; Seek</b>
3:00 – 6:00 PM	<b>Registration/Exhibits Open</b>
5:00 – 5:15 PM	<b>Welcome</b>
5:15 – 6:30 PM	<b>ITP Through the Ages: A historical look at what we have learned and what we still don't know</b>
6:30 – 7:15 PM	<b>Patient Mixer</b>
7:15 – 8:45 PM	<b>Inquire &amp; Inspire: patients ask the experts and share personal journeys</b> (small group sessions) <ul style="list-style-type: none"> <li>• Patients &amp; Caregivers</li> <li>• Canadian Patients &amp; Caregivers</li> <li>• For Teens Only</li> </ul>

## SATURDAY, JULY 22

8:00 – 9:00 AM	<b>Registration / Continental Breakfast / Exhibits Open</b>
9:00 – 10:15 AM	<b>How do I know I have ITP and what does that mean?</b> <ul style="list-style-type: none"> <li>• Establishing the diagnosis of ITP</li> <li>• When, why, and how you should ask for a second opinion</li> <li>• The role of the platelet count in ITP management</li> <li>• What if I don't have ITP?</li> </ul>
10:15 – 10:30 AM	<b>Break</b>
10:30 – 11:30 AM	<b>Inquire &amp; Inspire: patients ask the experts and share personal journeys</b> (small group sessions) <ul style="list-style-type: none"> <li>• Rare bleeding disorders during adolescence, pregnancy, and menopause – for women only</li> <li>• ITP in Seniors</li> <li>• Teen session, for parents of teens (transitioning from high school to college, pediatric hematologist to adult hematologist)</li> <li>• For Men Only</li> </ul>

11:30 AM – 1:00 PM	<b>The impact of ITP on Quality of Life</b> <ul style="list-style-type: none"> <li>• Bleeding and Fatigue</li> <li>• Travel and Sports</li> <li>• Cognitive function in ITP</li> <li>• In Sickness and In Health: How Chronic Medical Illness and Rare Diagnoses Impact Families and Couples</li> </ul>
1:00 – 2:00 PM	<b>Lunch Break with PDSA Medical Advisors</b>
2:00 – 3:00 PM	<b>Treatment strategies and emerging therapies for ITP</b> <b>What is a clinical trial and how does it work?</b>
3:00 – 3:15 PM	<b>Break</b>
3:15 – 4:15 PM	<b>Concurrent Sessions:</b> <ul style="list-style-type: none"> <li>• ITP in Adults: Q &amp; A</li> <li>• An Update on Pediatric ITP: differentiating primary ITP, IPD, and PID</li> </ul>
4:15 – 4:30 PM	<b>Break</b>
4:30 – 5:15 PM	<b>Shared Decision Making: making the right choices in ITP management</b> (to include fireside chat with two patients)
5:15 – 5:30 PM	<b>Announcements</b>
6:30 – 7:30 PM	<b>Dinner Program</b>
8:00 – 10:30 PM	<b>Family Fun Event – Cruise on Chicago's First Lady with an architectural tour on the river and fireworks</b>

## SUNDAY, JULY 23

9:00 – 10:30 AM	<b>Continental Breakfast</b> <b>Support Group Facilitators' Breakfast</b> (pre-registration requested)
10:30 – 11:30 AM	<b>Keynote Speaker: The Mind Body Connection: Medical Trauma, Rare Disease, and Strategies for Resilience</b>
11:30 – 11:45 AM	<b>Break</b>
11:45 AM – 12:45 PM	<b>Living with ITP: Patients share their stories</b>
12:45 – 1:00 PM	<b>Closing Remarks</b>

- NOTES:**
- Agenda and speakers subject to change
  - A separate track for teens and young adults will run Friday and Saturday
  - Kids Kamp will run during all conference sessions



## Special Events

To celebrate our patient community and PDSA's 25<sup>th</sup> anniversary, we are pleased to host the following special events for ITP Conference 2023 attendees and their families over the weekend.



### **Pump It Up For Platelets! Hike & Seek**

July 21, 2023 • 8-9am

Start Friday off on the right foot and join us for a special Pump It Up For Platelets! Hike & Seek in downtown Chicago before ITP Conference 2023 begins. We'll

explore the city together for this fun, planned adventure, taking off from the Swissôtel. With a list of landmarks to seek and find, participants will have the opportunity to meet other conference attendees and enjoy the morning outdoors. Please note: this event is complimentary, and registration is required. The first 100 registrants will receive an exclusive Pump It Up For Platelets! t-shirt.

### **Saturday Night Family Fun Event – Architectural Riverboat Cruise**

July 22, 2023 • 8-10:30pm

After a fulfilling day of conference programming, it's time for some fun. Conference attendees and their families are invited to join us for a special 2 ½ hour architectural cruise on Chicago's First Lady riverboat. We'll wind our way down the Chicago River to take in the city's legendary architecture and history, narrated by a professionally trained architectural guide; get a taste of iconic Chicago deep-dish pizza; and revel in the beauty of an exciting fireworks celebration above it all. This special boat cruise is complimentary for conference attendees and their families, but space is limited. Preregistration is required.



## Conference Location



All meeting activities will be held at the **Swissôtel in downtown Chicago**. Designed by renowned Chicago architect Harry Weese, Swissôtel Chicago is an award-winning luxury hotel overlooking the Chicago River and Lake Michigan, and just steps from the Magnificent Mile. The distinctive 4-diamond, all-glass hotel offers spectacular wrap-around views from Navy Pier to Millennium Park, 662 guest rooms and suites, five premier ballrooms, state-of-the-art penthouse fitness center, and spotless European-style service.

If you plan to stay at the **Swissôtel Chicago**, please reserve your room as soon as possible to receive our special conference rate of \$165 a night (king or queen/queen), plus tax. **This rate is for 2 adults or a family of 4 with children under age 18.** This special PDSA rate is also available for conference attendees three days before and three days after the conference. The rate applies to reservations that are made by **June 30, 2023, as long as rooms at the hotel are available.** *Hotel reservations cannot be made until your conference registration is finalized.* Hotel rates for physicians and industry partners is \$254 a night.



# Conference Speakers



**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.



**Stacey J. Feuer, PsyD, MLD**

Dr. Stacey Feuer is the Director of Health Psychology for a large medical group in the Chicago area, and a licensed Clinical Health Psychologist. She additionally holds a master's degree in Leadership Development in Healthcare and the Biotechnology Industry. Dr. Feuer has a passion for working with individuals living with chronic medical illness as psychologist, healthcare consultant, and speaker. Through her work, she helps patients live healthier, more resilient lives while coping with a wide range of medical conditions. She specializes in individuals living with the special challenges of rare, ultra-rare, and/or genetic diseases. Dr. Feuer believes that health is more than just the sum of our physical ailments. She aims to help patients develop and increase an overall sense of well-being in their daily lives even while living with chronic medical issues. Dr. Feuer was diagnosed with Gaucher Disease Type 1 in 1997, and has been a speaker and advocate in the Gaucher and rare disease community for more than twenty-five years. She enjoys educating and connecting with patients, families, medical providers, and industry leaders about the experiences of those living with a rare, genetic disorder.



**Terry Gernsheimer, MD**

Dr. Terry Gernsheimer is Professor of Medicine at the University of Washington School of Medicine, Medical Director of the Platelet Antibody Laboratory at the Puget Sound Blood Center, and Director of Transfusion Services at the University of Washington Medical Center and the Seattle Cancer Care Alliance. Dr. Gernsheimer's major research interests include the diagnosis, treatment and pathophysiology of autoimmune platelet disorders as well as several aspects of transfusion medicine and medical education.



**Rachael Grace, MD, MMSc**

Dr. Rachael Grace is a Pediatric Hematologist at the Dana-Farber/Boston Children's Cancer and Blood Disorders Center and an Associate Professor at Harvard Medical School in Boston, Massachusetts. She is the Medical Director of the Hematology Clinical Research Program at Boston Children's Hospital and is recipient of the Blanche P. Alter Investigatorship in Hematology. Dr. Grace received her MD from Brown University and received her Masters in Medical Science from Harvard Medical School. She completed her pediatrics residency at Boston Children's Hospital and pediatric hematology/oncology fellowship at the Dana-Farber/Boston Children's Cancer and Blood Disorders Center. She is the director of the pediatric ITP Consortium of North America (ICON), a collaboration of more than 50 sites in North America focused on improving ITP care for children. She is a leading investigator for multiple observational and interventional research studies for children with ITP and is involved in national ITP guideline initiatives. Dr. Grace's clinical and research interests are focused on improving outcomes of children with immune cytopenias and rare congenital hemolytic anemias.



**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, MSTR**

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.



**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





# ITP Conference 2023 Registration Form

July 21 – 23 Chicago, IL

Register online at [www.pdsa.org/conferences](http://www.pdsa.org/conferences) or mail this form to:

PDSA 8751 Brecksville Road, Suite 150, Cleveland, OH 44141

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 American (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 as Director of Transfusion Medicine Research of the Toronto Platelet Immunobiology Group. He joined Lund University in 2016 as a Professor of Transfusion Medicine of St. Michael's Hospital. 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.

## General Registration Information\* – person attending conference

(see additional lines for guest names below)

**Full payment is due at time of registration.**

(Mr./Ms./Mrs./Dr.) First Name Last Name Suffix

Address

City State/Province ZIP Code Country

Phone (Home, Business or Mobile) Email

## Additional guests or family members

**Please include name and city/state/country for each additional guest for their name badge**

Guest name Guest name Guest name

City State/Province Country

☐ **Special needs:** I have special dietary needs. Please explain:

(Please note that PDSA cannot make special accommodations for specific dietary requirements)

## Applying for a partial scholarship

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

**Please see the Registration Information page following this form for information and instructions on how to apply.**

**CONTINUED ON THE NEXT PAGE >**

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

## Total fees and payment

Registration includes all sessions, receptions, continental breakfasts on Saturday and Sunday and Saturday lunch.

If you are not already a member of PDSA, you can become one by choosing to pay the \$25 membership fee and then choosing the discounted cost of the Conference under the Member Price column. By becoming a member, you will receive the 28-page quarterly newsletter, *The Platelet News* and discounted rates for the annual ITP Conference.

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

**\*\*THERE WILL BE NO ON-SITE REGISTRATION\*\***

**Early Bird Registration: Through June 30, 2023** After June 30, 2023 registration prices will increase.

	MEMBER PRICE	NON-MEMBER PRICE	
Individual	\$140	\$160	\$ _____
Children ages 5-12	\$50	\$60	\$ _____
Children 4 and under	FREE	FREE	\$ <b>FREE</b>
One Day Pass Registration (Either Friday/Saturday or Saturday/Sunday)	\$100	\$120	\$ _____
PDSA Circle of Hope Member Registration (limit of 2)			\$ <b>FREE*</b>
~or~ PDSA Support Group Facilitator Registration (limit of 1)			\$ <b>FREE*</b>

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

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

**TOTAL REGISTRATION** \$ \_\_\_\_\_

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

Name on Credit Card: \_\_\_\_\_

Credit Card Number: \_\_\_\_\_

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

Your CSC Code is the 3 digit code on the back of your card for Master Card, Visa or Discover or 4 digit code on the front of AMEX

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

**Cancellation Policy:** If you need to cancel your registration for the Conference, you must submit your request to cancel in writing prior to June 30, 2023. All fees less a \$50 administrative charge will be refunded if a written request is received before the June 30th deadline.

**After June 30, 2023, no refunds will be issued.**

**Hotel Reservations:** All Conference sessions, meals and receptions will take place at Swissôtel, Chicago, IL. PDSA has secured room rates for patients, caregivers and family attending the conference at \$165 per night (king or queen/queen). A separate rate is available for industry and physician attendees. Once your Conference registration has been made, you will be sent the information to make your hotel accommodations. Hotel rooms cannot be booked prior to your conference registration.

**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 via email at [jshy@pdsa.org](mailto:jshy@pdsa.org).

# Registration Information

**Scholarships:** Partial scholarships to attend the ITP Conference are available. Please send a completed conference registration form, along with a letter describing your diagnosis, financial need, and the benefit you hope to derive from attending the conference to Brenda Foster at [bfoster@pdsa.org](mailto:bfoster@pdsa.org), or by mail to PDSA, 8751 Brecksville Road, Suite 150, Cleveland, OH 44141. **Deadline to apply for a scholarship is June 27, 2023. Applicants must be a PDSA member.**

**Cancellation Policy:** See the registration form for details. **After June 30, 2023, 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 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.

**COVID-19 Policy:** COVID-19 vaccination for conference participants is recommended but not mandated. For the protection of those attending the conference who may be at risk of infection, we strongly recommend that masks be worn at the meeting.

## More Information

Visit: [www.pdsa.org](http://www.pdsa.org) • Call: (440) 746-9003 • Email: [pdsa@pdsa.org](mailto:pdsa@pdsa.org)





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