



Platelet Disorder Support Association

# ITP CONFERENCE 2025

# 25<sup>TH</sup>

*The premier patient event*

ANNUAL

July 25 - July 27 | Philadelphia, PA

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# Know what counts.

Living with ITP adds up to more than managing platelet counts. Often, there's also the fatigue, uncertainty, and questions that don't always have easy answers. ITP isn't just about the numbers. It's about knowing what counts—to you. **Join the conversation at our booth and Saturday's dinner program.**



**Find resources you can count on.  
[understandingITP.com](https://www.understandingITP.com)**



# ITP CONFERENCE 2025 ABOUT PDSA

The **Platelet Disorder Support Association (PDSA)** is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support. Patient-founded in 1998 to educate and empower those impacted by ITP and other rare platelet and bleeding disorders, PDSA is now a powerful force serving and unifying the global community of patients, practitioners, caregivers, advocates, and key disease stakeholders. PDSA is committed to building awareness, educating the global community, and providing critical connections and resources that empower patients to take charge of their disease and encourage practitioners to exercise patient-centered medical care. PDSA receives no federal funding. It never has. Charitable gifts from our individual and corporate donors, membership contributions, and inspiring awareness and philanthropic events coordinated by committed volunteers energize, uphold and preserve our mission.

## PDSA Programs and Services

**PATIENT EDUCATION** - PDSA is home to the most extensive patient-focused library of current ITP disease, treatment and research information available online and in print.

**PATIENT SUPPORT** - Our patient-centered programs and services connect ITP patients and caregivers, build awareness, promote community, and empower ITP patients to take control of their disease.

**AWARENESS & ADVOCACY** - We are committed to ongoing awareness, advocacy and collaborations with other patient advocacy groups, researchers and government agencies to drive public policy, develop new treatment options and fund research to find a cure.

**PLATELET DISORDER RESEARCH** - We support investigations that examine the pathogenesis and management of primary ITP and present the most promising outlook to significantly improve diagnosis, therapies, and patient quality of life.

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Rachael Grace, MD, MMSc\*  
Craig Kessler, MD\*  
David Kuter, MD, DPhil\*

*\* Conference Speaker*

Michele Lambert, MD, MSTR\*  
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# ITP CONFERENCE 2025

# AGENDA

## FRIDAY, JULY 25

1:00 – 5:00 PM	Registration/Exhibits Open.....Ballroom Foyer
3:00 – 3:15 PM	<b>Welcome</b> .....Ballroom Caroline Kruse, PDSA President and CEO
3:15 – 4:15 PM	<b>The Phases of ITP</b> .....Ballroom Terry Gernsheimer, MD
	<b>Navigating the Patient Journey: From newly diagnosed to chronic ITP</b> .....Ballroom David Kuter, MD, DPhil and Diane Nugent, MD
	<b>ITP in Teens: A medical overview</b> .....Mt. Vernon Rachael Grace, MD, MMSc and Michele Lambert, MD, MSTR
4:15 – 5:00 PM	<b>BREAK</b>
5:00 – 6:00 PM	<b>Sobi-sponsored Educational Dinner Program and PDSA Trivia</b> .....Ballroom
6:00 – 6:15 PM	<b>BREAK</b>
6:15 – 7:30 PM	<b>Inquire &amp; Inspire: Patients ask the experts &amp; share personal journeys (small group sessions)</b>
	<b>Canadian Patients &amp; Caregivers</b> .....Graff House Kristin Hunt, MDCM, MSc, FRCP (C) and Ishac Nazy, PhD
	<b>For Teens Only</b> .....Montpelier Michael Tarantino, MD and staff
	<b>Other groups based on geographic location</b> .....Grange, Mt. Vernon, Monticello, Stenton James Bussel, MD, Douglas Cines, MD, Annemarie Fogerty, MD, Terry Gernsheimer, MD, Rachael Grace, MD, MMSc, Craig Kessler, MD, David Kuter, MD, DPhil, Michele Lambert, MD, MSTR, Howard Liebman, MD, Diane Nugent, MD

## SATURDAY, JULY 26

\*Enjoy free, secure WiFi on Saturday! Password: KnowWhatCounts

WiFi Sponsored by: **sanofi**

8:00 – 9:00 AM	Registration/Exhibits Open.....Ballroom Foyer
	Continental Breakfast.....Stenton & The Commons

9:00 AM – 10:15 AM	<p><b>The Pathophysiology of ITP: What we have learned these past 25 years</b>.....Ballroom Ishac Nazy, PhD</p> <p><b>When to Involve an Immunologist in Your ITP Journey: A professional and patient perspective</b>.....Ballroom Kristin Hunt, MDCM, MSc, FRCP (C)</p> <p><b>When It's Not ITP: Testing and genetics</b>.....Ballroom Michele Lambert, MD, MSTR</p>
10:15 – 10:30 AM	<b>BREAK</b>
10:30 – 11:30 AM	<p><b>Inquire &amp; Inspire: Patients ask the experts &amp; share personal journeys (small group sessions)</b></p> <p><b>General ITP Questions</b>.....Bedford, Graff House, Monticello James Bussel, MD, Douglas Cines, MD, David Kuter, MD, DPhil, Howard Liebman, MD, Diane Nugent, MD</p> <p><b>ITP in Children</b>.....Grange Rachael Grace, MD, MMSc, Michele Lambert, MD, MSTR, Michael Tarantino, MD</p> <p><b>For Women and Girls Only: Rare bleeding disorders during adolescence and pregnancy</b>.....Mt. Vernon Annemarie Fogerty, MD, Terry Gernsheimer, MD, Dee Terrell, PhD <i>Please note: Attendance is limited to women and girls only.</i></p> <p><b>ITP and Aging: Addressing the unique challenges</b>.....Ballroom Craig Kessler, MD</p>
11:30 – 11:45 AM	<b>BREAK</b>
11:45 AM – 1:00 PM	<p><b>Quality of Life in ITP: Fatigue, bleeding, oral health, cognitive impairment</b>.....Ballroom Terry Gernsheimer, MD, Craig Kessler, MD, David Kuter, MD, DPhil, Dee Terrell, PhD</p>
1:00 – 2:00 PM	<b>Lunch Break with PDSA Medical Advisors</b> .....Stenton & The Commons
2:00 – 3:00 PM	<p><b>ITP: New targets, new agents, and new possibilities</b>.....Ballroom James Bussel, MD, David Kuter, MD, DPhil, Howard Liebman, MD</p>
3:00 – 3:15 PM	<b>BREAK</b>
3:15 – 4:15 PM	<p><b>ITP in Adults: Q&amp;A</b>.....Ballroom James Bussel, MD, Douglas Cines, MD, Craig Kessler, MD, David Kuter, MD, DPhil, Howard Liebman, MD, Diane Nugent, MD</p> <p><b>ITP in Children: Q&amp;A</b>.....Mt. Vernon Rachael Grace, MD, MMSc, Michele Lambert, MD, MSTR, Michael Tarantino, MD</p> <p><b>Challenges for Women with ITP Later in Life</b>.....Monticello Annemarie Fogerty, MD and Terry Gernsheimer, MD</p>

4:15 – 4:30 PM	BREAK
4:30 – 5:15 PM	<b>Access to Care: Navigating the maze of ITP treatments.....</b> Ballroom Michele Lambert, MD, MSTR and Becky Burns, COO, Bleeding & Clotting Disorders Institute
5:15 – 5:30 PM	<b>Announcements.....</b> Ballroom Caroline Kruse, PDSA President and CEO
5:30 – 6:30 PM	BREAK
6:30 – 7:30 PM	<b>Sanofi-sponsored Educational Dinner Program “Know What Counts: An Open Conversation about ITP” .....</b> Ballroom
8:00 – 10:00 PM	<b>Saturday Evening Fun Event</b> Meet in hotel lobby

## SUNDAY, JULY 27

9:00 – 10:30 AM	<b>Continental Breakfast.....</b> Stenton & The Commons <b>Support Group Facilitators’ Breakfast.....</b> Mt. Vernon
10:30 – 11:30 AM	<b>Meeting the Challenge of Rare Disease in the Family: 25 years of lessons learned.....</b> Ballroom Al Freedman, PhD
11:45 AM – 12:45 PM	<b>Living with ITP: Patients share their stories.....</b> Ballroom
12:45 – 1:00 PM	<b>Closing Remarks.....</b> Ballroom

\*Inquire & Inspire: Patients ask the experts and share personal journeys (small group sessions): Room assignments included in your name badge

\*\*A separate track for teens and young adults can be found on the next page

\*\*\*Agenda and speakers subject to change

# ITP KIDS KAMP

will be meeting in the **Randolph House** Meeting Room, on the **Lower level!**

## FRIDAY

3 PM – 4:15 PM  
6:15 PM – 7:30 PM

## SATURDAY

9 AM – 1 PM  
2 PM – 5:30 PM

## SUNDAY

10:30 AM – 1 PM



**AGES 5-12**

## ACTIVITIES:

- GAMES
- MOVIES
- ARTS & CRAFTS
- AND MORE!

\*Children must be picked up during scheduled meals and breaks



# ITP CONFERENCE 2025

## TEEN TRACK

### FRIDAY, JULY 25

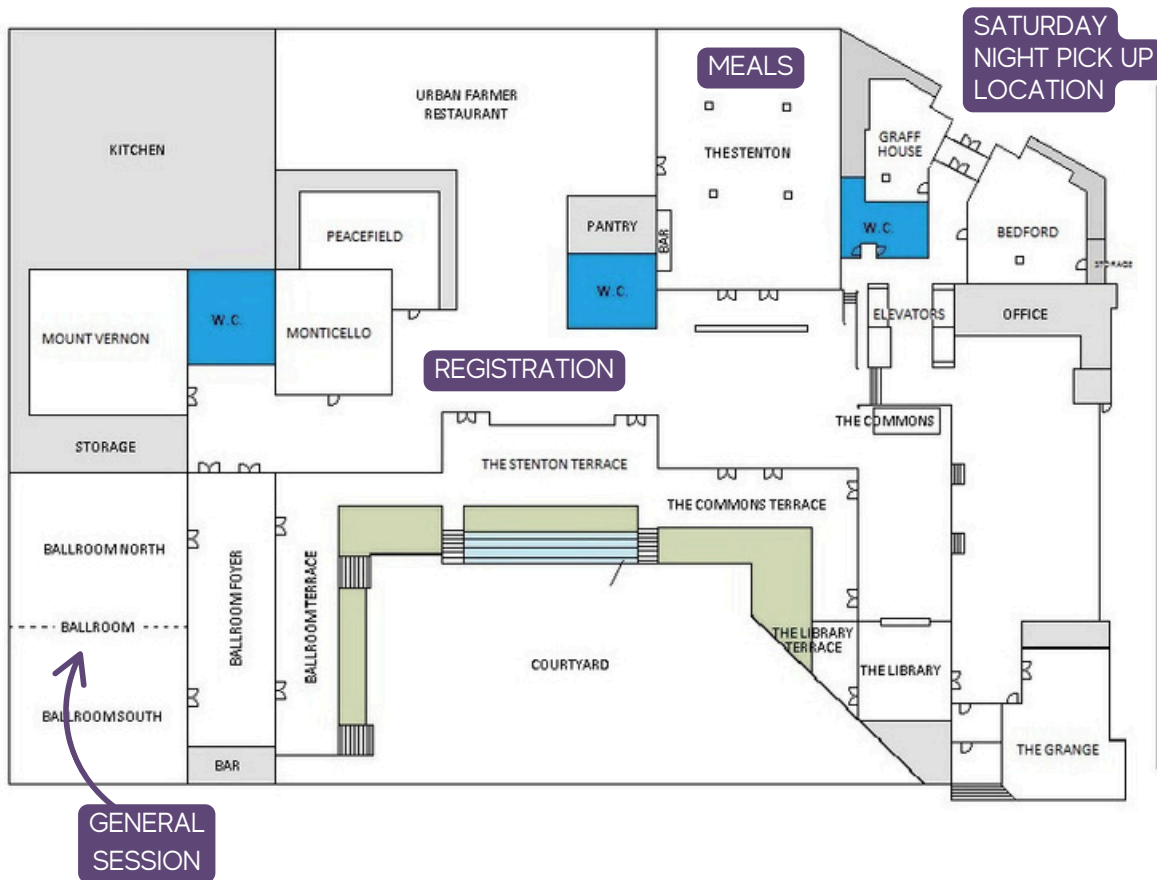
3:00 - 3:10 PM	<b>Welcome</b> .....Ballroom Caroline Kruse, PDSA President and CEO
3:10 - 4:15 PM	<b>Parents and Teens Session</b> .....Mt. Vernon - lobby level Rachael Grace, MD, MMSc, and Michele Lambert, MD, MSTR
4:15 - 5:00 PM	<b>BREAK</b>
5:00 - 6:00 PM	<b>Sobi-sponsored Educational Dinner Program and PDSA Trivia</b> .....Ballroom Sponsored by Sobi
6:00 - 6:15 PM	<b>BREAK</b>
6:15 - 7:30 PM	<b>Inquire &amp; Inspire: Teen gathering</b> .....Montpelier - lower level Michael Tarantino, MD and staff

### SATURDAY, JULY 26

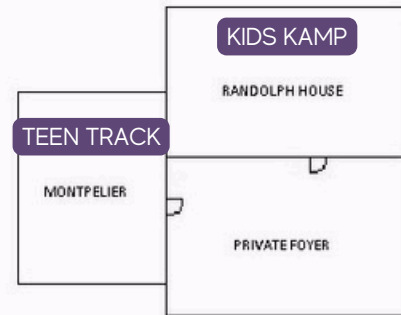
8:00 - 9:00 AM	<b>Breakfast together</b> .....Stenton meeting room - lobby level
9:00 - 9:15 AM	<b>Group Picture; Photo Booth</b> .....Ballroom Foyer
9:15 - 10:15 AM	<b>Teens and Advocacy: How you can make a difference</b> .....Montpelier - lower level Jim Romano, Care and Cure Partners
10:15 - 10:30 AM	<b>BREAK</b>
10:30 - 11:30 AM	<b>Inquire &amp; Inspire</b> .....Breakout Rooms - lobby level
11:30 - 11:45 AM	<b>BREAK</b>
11:45 AM - 1:00 PM	<b>Group Project</b> .....Montpelier - lower level
1:00 - 2:00 PM	<b>LUNCH</b>
2:00 - 3:00 PM	<b>Scavenger Hunt</b> .....Montpelier - lower level
3:00 - 3:15 PM	<b>BREAK</b>
3:15 - 5:30 PM	<b>Free Time</b> ( <i>pool, courtyard, etc.</i> )
5:30 - 6:30 PM	<b>BREAK</b>
6:30 - 7:30 PM	<b>Sanofi-sponsored Educational Dinner Program "Know What Counts: An Open Conversation about ITP"</b> .....Ballroom
8:00 - 10:00 PM	<b>Saturday Evening Fun Event</b> Meet in hotel lobby

# THE LOGAN HOTEL

## LOBBY LEVEL



## LOWER LEVEL



Shop our unique collection of ITP Awareness items,  
located in the Ballroom Foyer!

### FRIDAY

1:00 PM - 4:30 PM



### SATURDAY

8:00 AM - 5:45 PM



### SUNDAY

9:00 AM - 1:00 PM





*"Walking into my first PDSA conference was so exciting and it only got better from there. I just loved being around so many people who understood."*



*"I discovered that there are options, and that I have a voice in my care."*

# 25 Years of ITP Conferences with YOU!



*"As a spouse it was helpful for me to understand all of the potential issues that my wife was facing, or could face, and know that there is a community to reach out to. I no longer felt helpless in advocating or supporting her."*



*"One of the greatest blessings of my life has been my association with the PDSA"*



*"I had never met anyone with ITP before and made some life-long friends!"*



*"Forever grateful!"*



# ITP CONFERENCE 2025 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 patient 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. In 2012, he received the King Faisal Prize for Medicine, known as the Arab Nobel Prize. Dr. Bussel also serves on the PDSA Board of Medical Advisors.



## **Douglas Cines, MD**

Dr. Douglas Cines is a hematologist and researcher at the University of Pennsylvania. Dr. Cines is a central figure in the field of immune thrombocytopenia, and his research focuses on the breakdown of tolerance in ITP including consideration of secondary ITP and the evolution of antiplatelet antibodies and the potential for epitope spreading. He has been published in several notable publications, including New England Journal of Medicine and Blood. Dr. Cines also serves on the PDSA Board of Medical Advisors.



## **Annemarie Fogerty, MD**

Dr. Annemarie Fogerty is a Hematology Specialist in Boston, MA, with over 18 years of experience. She graduated from New York University School of Medicine in 2003, then went on to internal medicine residency at Massachusetts General Hospital. She completed her fellowship training at the Dana Farber Cancer Institute. She currently serves as the Clinical Director for Hematology and Director of Reproductive Hematology at both Massachusetts General Hospital and NewtonWellesley Hospital. Her particular areas of clinical expertise and research focus on thrombocytopenia and thrombosis in the pregnant patient. Dr. Fogerty also serves on the PDSA Board of Medical Advisors.



### **Al Freedman, PhD**

Dr. Al Freedman is a psychologist, educator, and rare disease advocate with more than two decades of experience working with individuals and families affected by rare diseases and disabilities.

Dr. Freedman is inspired by his personal journey as the father of Jack, who lived with spinal muscular atrophy (SMA) for 26 years as well as his professional training and experience as an educator to provide counseling and consultation. He works with families, advocacy organizations, pharmaceutical companies, healthcare organizations, and schools to create meaningful support systems and impactful change within the rare disease and disability communities.



### **Terry Gernsheimer, MD**

Dr. Terry Gernsheimer is Professor of Medicine at the University of Washington School of Medicine and the Medical Director of Transfusion at the Seattle Cancer Care Alliance. Dr. Gernsheimer's research focuses on the pathophysiology and treatment of immune platelet disorders and pathologic immune responses associated with transfusion. She has clinical research interest in transfusion management of the hematopoietic stem cell transplant patient and surgical bleeding in patients undergoing solid organ transplant and cardiovascular procedures. She has made significant contributions toward understanding the pathophysiology and management of ITP. Dr. Gernsheimer also serves on the PDSA Board of Medical Advisors.



### **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. Dr. Grace also serves on the PDSA Board of Medical Advisors.



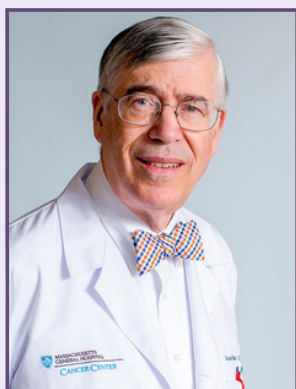
### **Kristin Hunt, MDCM, MSc, FRCPC**

Dr. Kristin Hunt was diagnosed with chronic ITP at the age of 12 years old. She started volunteering and fundraising for PDSA in 2010 where she co-founded the ITP Kids Camp and she currently serves on PDSA's patient research panel. Determined to continue helping patients, she decided to build her career in medicine. She holds a Bachelor of Science in Microbiology and Immunology, and a Master of Science in Immunology from McGill University in Montreal, QC. She obtained her medical degree from McGill University and during that time, she co-founded McGill's first Rare Disease Interest Group. Kristin completed her pediatrics residency training at Queen's University in Kingston, Ontario and recently became a licensed pediatrician in June 2024. She is now completing her second and final year of subspecialty training in Pediatric Allergy and Clinical Immunology at the Hospital for Sick Children in Toronto, Ontario. Dr. Hunt hopes to use both her personal and professional experiences to continue helping ITP patients and all those affected by immune-mediated disorders.



### **Craig Kessler, MD**

Dr. Craig Kessler is professor of Medicine and Pathology and Section Chief of Hematology at Georgetown University, where he also serves as the Director of the Coagulation Laboratory. A graduate of Tulane School of Medicine, Dr. Kessler received his speciality training in hematology and oncology at The Johns Hopkins Hospital. An international expert in the area of disorders of coagulation, Dr. Kessler has a particular interest in hemophilia. He also has expertise in the treatment of hematologic malignancies. Dr. Kessler also serves on the PDSA Board of Medical Advisors.



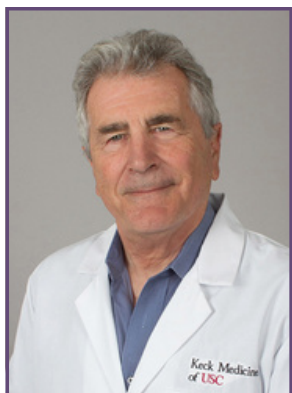
### **David Kuter, MD, DPhil**

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 and Chief of Hematology at the Massachusetts General Hospital. 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. Dr. Kuter also serves on the PDSA Board of Medical Advisors.



### **Michele P. Lambert, MD, MSTR**

Dr. Michele 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. Dr. Lambert also serves on the PDSA Board of Medical Advisors.



### **Howard Liebman, MD**

Dr. Howard Liebman is Professor of Medicine and Pathology at the University of Southern California (USC) Keck School of Medicine, Los Angeles, CA. He serves as Medical Director of the Special Hemostasis Laboratory at the USC 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. Dr. Liebman also serves on the PDSA Board of Medical Advisors.



### **Ishac Nazy, PhD**

Dr. Ishac Nazy is an associate professor of Medicine, Hematology & Thromboembolism at McMaster University. His research interests include the specific interactions between antibodies and their target antigens on platelets, leading to thrombocytopenia and/or thrombosis. Heparin induced thrombocytopenia and immune thrombocytopenia are great models for identifying key factors involved in the pathogenesis of the immune responses leading to low platelet counts. Dr. Nazy's research focuses on the cellular and humoral immunity and the downstream effects on platelet physiology.



### **Diane Nugent, MD**

Dr. Diane Nugent is a Clinical Professor, Department of Pediatrics, University of California, Irvine School of Medicine and PDSA Medical Advisor. 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 (NHLBI) 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. Dr. Nugent also serves on the PDSA Board of Medical Advisors.



### **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 and founded The Bleeding and Clotting Disorders Institute in 2010. Dr. Tarantino also serves on the PDSA Board of Medical Advisors.



### **Deirdra "Dee" Terrell, PhD**

Dr. Dee Terrell is an Associate Professor of Epidemiology in the Department of Biostatistics and Epidemiology at the University of Oklahoma Health Sciences Center and Assistant Dean for Sovereignty, Opportunity, Belonging, & Engagement. Her research interests include diseases of platelet disorders and improving life after recovery from thrombotic thrombocytopenic purpura (TTP). She has published over 70 peer-reviewed articles and is a National Institute of Health K01 awardee. Her K01 grant proposal focuses on improving the lives of patients after they recover from TTP. Her career development training focused on the theory and application of patient-reported outcomes. She is also an active member of the Guideline Oversight Subcommittee for the American Society of Hematology.



ITP CONFERENCE 2025

# SPECIAL PROGRAMS

## SATURDAY EVENING FUN EVENT

Join fellow patients, caregivers, and families Saturday evening after the Dinner Program for a special 90 minute **guided tour aboard an open-top, double-decker bus**. Explore nearly **30 iconic Philadelphia landmarks**, including Independence Hall, the Liberty Bell, and Ben Franklin's grave.

Pick-up and drop-off will be at The Logan Hotel. The tour will begin at 8:00pm EDT.

Registration for this event is closed.



## SUNDAY KEYNOTE SPEAKER

Al Freedman, PhD

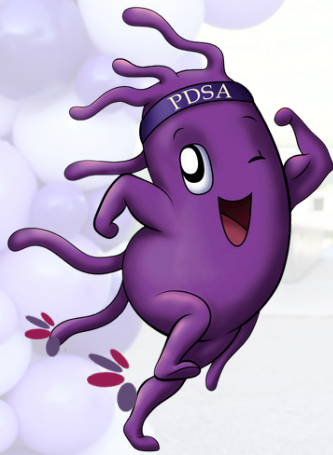


Sunday morning programming kicks off with our **keynote speaker, Al Freedman, PhD!** Dr. Al is a psychologist, educator, and rare disease advocate with more than two decades of experience working with individuals and families affected by rare diseases and disabilities.

Dr. Al is inspired by his personal journey as the father of Jack, who lived with spinal muscular atrophy (SMA) for 26 years as well as his professional training and experience as an educator to provide counseling and consultation. He works with families, advocacy organizations, pharmaceutical companies, healthcare organizations, and schools to create meaningful support systems and impactful change within the rare disease and disability communities.

# Pump It Up For Platelets!

Going the distance for the ITP community



## 2025 Upcoming Events

**August 9** - Locust Grove, VA - Classic Car Show

**September 20** - Detroit, MI

**September 20** - Highland, IL - Annual Devin Bowl

**September 27** - London, ON, Canada

**October 25** - Columbus, OH

**October 26** - Orange County, CA

**November 8** - Northern California - Hybrid

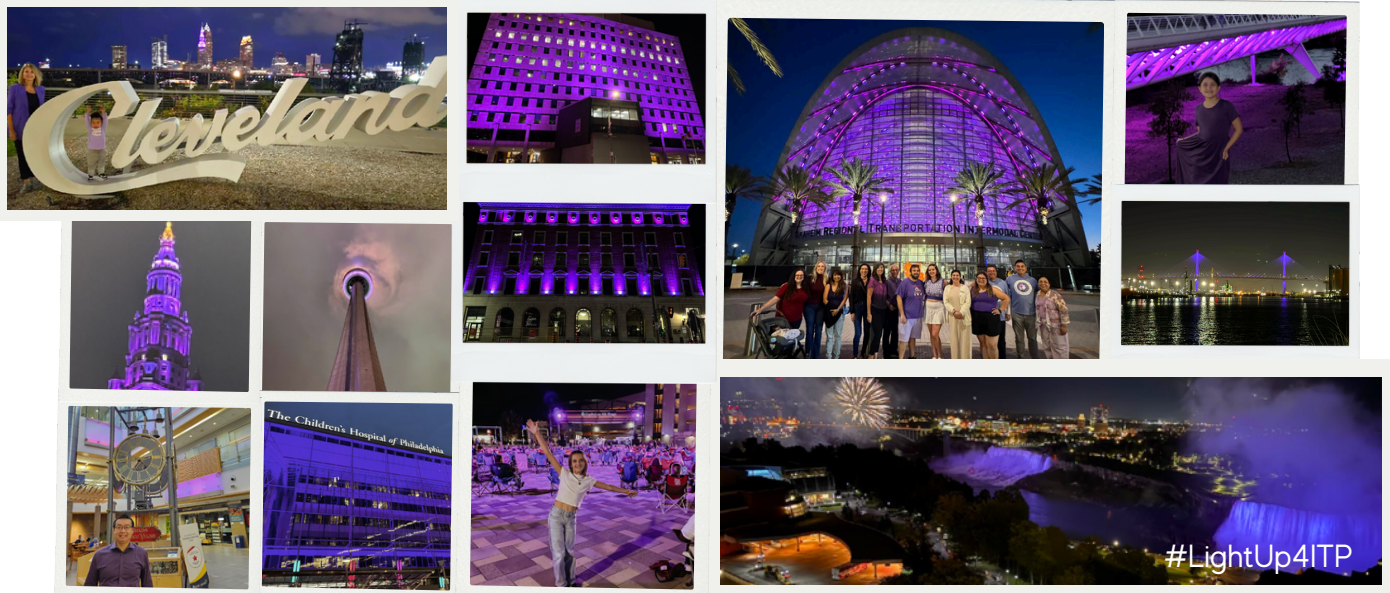
**Dates TBD:** College Station, TX; Meridian, MS

Join one of our community events or host your own! No event is too big or small, and events can take place in-person or virtually. *PDSA is here to help you every step of the way!*



## Shining Light on ITP

September is ITP Awareness Month, and we need YOUR help to Light Up For ITP!



Monuments lit purple across the U.S. during ITP Awareness Month 2024

Learn more at [pdsa.org/itp-awareness-month](https://pdsa.org/itp-awareness-month)

# PDSA's ITP Patient Connect



## Patient & Caregiver Support Network



### We are here when and where you need us!

- Over 67 local support groups
- Parents of Kids with ITP Teleconference
- PDSA.org discussion forum

Find strength, support, and community with ITP Patient Connect  
Visit [pdsa.org/support-groups](https://pdsa.org/support-groups) for meeting dates and details

Support Group  
Facilitators'  
**Breakfast  
and  
Workshop**

**Sunday, July 27**  
9:00-10:30 AM ET  
Mt. Vernon

Those interested in starting a support group are welcome to attend.  
Questions? See Jody Shy.

# TOGETHER, WE KEEP ITP PATIENTS AT THE CENTER.

## 27 Years of ITP Leadership PDSA Remains *by Patients for Patients*

PDSA intimately understands the ITP patient experience. Founded by an ITP patient in 1998, we remain patient-led today. The patient perspective is a differentiator for PDSA and the reason we are so passionate about our focused efforts in **EDUCATION**, **ADVOCACY**, **RESEARCH**, and **SUPPORT**.

EDUCATION



ADVOCACY



ITP  
PATIENTS

RESEARCH



SUPPORT

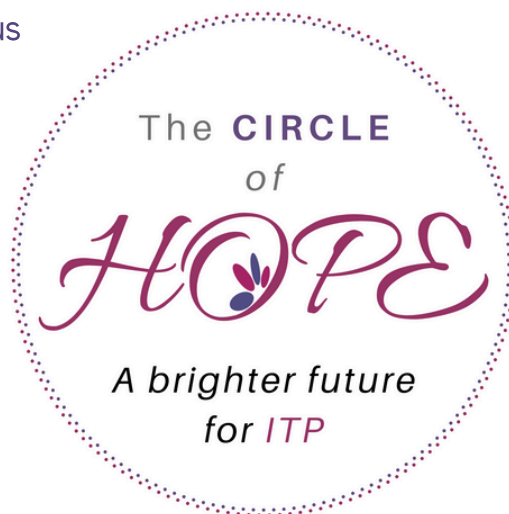


**SUPPORT PDSA TODAY! Visit [pdsa.org/give](https://pdsa.org/give)**

Join the distinguished society of supporters whose gracious gifts strengthen our financial independence, sustain our lifesaving work, and shape the future for ITP.

**Circle of Hope** Members donate or raise \$1,000 or more within a calendar year for PDSA, and serve as PDSA's philanthropic leaders.

Visit [PDSA.org/circle-of-hope](https://PDSA.org/circle-of-hope)



Cathy & Raul Aldama  
Theresa & Pete Anastasakis  
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Cheri & Derek Zimmerman  
Joyce & Dale Zimmerman



# ITP CONFERENCE 2025

## NOTES

- FRIDAY

[illegible]



FRIDAY

- Canadian Patients and Caregivers
- For Teens Only
- Other groups based on geographic location



- 
- This image shows a full page of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page, typical of notebook paper. There are no margins, text, or other markings on the page.



## SATURDAY

- General ITP Questions
- ITP in Children
- For Women and Girls Only: Rare bleeding disorders during adolescence and pregnancy
- ITP and Aging: Addressing the unique challenges



SATURDAY

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



SATURDAY

[illegible]



- ITP in Adults Q&A
- ITP in Children Q&A
- Challenges for Women with ITP Later in Life

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



SATURDAY

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



SUNDAY

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



**ITP CONFERENCE 2025**

# **SPECIAL THANKS**

We are thankful to the many people and corporations who helped make our 25th annual conference a success.

## **VOLUNTEERS AND AMBASSADORS:**

Cathy Aldama  
Raul Aldama  
Isaura Arias  
Anne Barry  
Talon Crist  
Jonathan Curtin  
Maria de Jesus  
Tammy Fassett  
Lindsey Hoefft  
Seppi Hoefft  
Barbara Jacobs

Jim Jacobs  
Joshua Kelly  
Karen Kelly  
Ken Kruse  
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Marsha O'Donnell  
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John Phillips

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Chris Proctor  
John Quirk  
Samantha Quirk  
Michael Scott  
Porcher Scott  
Allison Shy  
Brenda Shy  
Jon Shy  
Hannah Trueblood  
Tracy Trueblood

## **SPEAKERS:**

James Bussel, MD  
Douglas Cines, MD  
Annemarie Fogerty, MD  
Albert Freedman, PhD  
Terry Gernsheimer, MD  
Rachael Grace, MD, MMSc  
Kristin Hunt, MDCM, MMSc, FRCP (C)  
Craig Kessler, MD

David Kuter, MD, DPhil  
Michele Lambert, MD, MSTR  
Howard Liebman, MD  
Ishac Nazy, PhD  
Diane Nugent, MD  
Michael Tarantino, MD  
Deirdra "Dee" Terrell, PhD

## **PATIENT SPEAKERS:**

Holly Bruno  
Diana DiMeo  
Tammy Fassett  
Selena Gabat  
Joshua Kelly  
Kristen Prevost

**Platinum Sponsors:** Sanofi, Sobi

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ITP CONFERENCE 2025

# EXPLORING PHILADELPHIA

We are excited to host ITP Conference 2025 in Philadelphia, Pennsylvania—a city steeped in American history and cinematic fame! From the **Liberty Bell** and **Independence Hall** to the iconic “**Rocky Steps**” at the **Philadelphia Museum of Art**, Philly offers a unique blend of historic landmarks and beloved movie moments. We look forward to a weekend of education and connection, and hope that outside of conference hours you'll explore the many attractions this vibrant city has to offer. For more information on fun and family-friendly things to do in Philadelphia, visit [pdsa.org/things-to-do](https://pdsa.org/things-to-do).

## Betsy Ross House (including Once Upon a Nation Storytelling Benches)

239 Arch Street

## Congress Hall

Chestnut Street at 6th Street

## Delaware River Waterfront

121 North Christopher Columbus Blvd.

## Edgar Allan Poe National Historic Site

532 North 7th Street

## Independence National Historic Park

1 North Independence Mall

## LEGOLAND Discovery Center

500 W. Germantown Pike, Plymouth Meeting, PA

## Liberty Bell Center

101 South Independence Mall W.

## Longwood Gardens

1001 Longwood Road

## LOVE Sculpture

North 15th & Arch Streets

## Philadelphia Magic Gardens

1020 South Street

## Philadelphia Museum of Art

2600 Benjamin Franklin Pkwy

## Philadelphia Zoo

3400 West Girard Avenue

## Please Touch Museum

4321 Avenue of the Republic

## Reading Terminal Market

1136 Arch Street

## Rocky Statue and Steps

2600 Benjamin Franklin Pkwy

## The Franklin Institute

222 North 20th Street

## The President's House

600 Market Street

## United States Mint

151 North Independence Mall East

## Valley Forge National Historical Park

1400 North Outer Line Drive, King of Prussia



Liberty Bell Center



Delaware River Waterfront



Reading Terminal Market

**FACT: WE NEED MORE DATA**  
**TO TRULY UNDERSTAND HOW**  
**RARE ITP IS, WE NEED DATA,**  
**WE NEED *you!***

*CONSIDER ENROLLING  
IN OUR ITP REGISTRY  
TODAY!*



**ITP Patient Registry**



*We all have questions. Together let's find the answers.*

[pdsa.org/registry](https://pdsa.org/registry)



**HOW DID WE DO?**



**Take the ITP  
CONFERENCE 2025  
Survey by scanning  
this QR Code!**





## STRIVE FOR STABILITY, REACH FOR REMISSION\*

**NPLATE® OFFERS THE OPPORTUNITY TO REACH TREATMENT-FREE REMISSION\* WITH NO FOOD RESTRICTIONS, NO LIVER MONITORING AND NO KNOWN DRUG INTERACTIONS**

**For adults with immune thrombocytopenia (ITP) right after steroids, once-weekly Nplate® is a platelet booster that works with your body to boost and maintain platelet counts.**

**Visit the Amgen booth to access resources and learn about our patient support programs.**

\*Treatment-free remission defined as stopping all ITP treatments and maintaining platelet counts above 50,000 per microliter for at least 6 months. This occurred in 32% of patients (24/75) and was the secondary objective in the Nplate® clinical study. The main objective of the study was to look at how platelet count responded to Nplate®. In the study, 61% of patients achieved and maintained a platelet response for ≥ 11 months (n = 46/75).

### IMPORTANT SAFETY INFORMATION

**What is the most important information I should know about Nplate®?**

Nplate® may cause serious side effects, including:

- **Worsening of a precancerous blood condition to a blood cancer (leukemia):** Nplate® is not for use in people with a precancerous condition called myelodysplastic syndromes (MDS), or for any condition other than immune thrombocytopenia (ITP). If you have MDS and receive Nplate®, your MDS condition may worsen and become an acute leukemia. If MDS worsens to become acute leukemia you may die sooner from the acute leukemia.
- **Higher risk for blood clots:**
  - You may have a higher risk of getting a blood clot if your platelet count becomes high during treatment with Nplate®. You may have severe complications or die from some forms of blood clots, such as clots that spread to the legs (Deep Vein Thrombosis), lungs (Pulmonary Embolism) or that cause heart attacks or strokes.
  - You may get blood clots in the veins of your liver (Portal Vein Thrombosis) with or without chronic liver disease that may affect your liver function.

#### • What are the possible side effects of Nplate®?

Nplate® may cause serious side effects. See "What is the most important information I should know about Nplate®?"

The most common side effects of Nplate® in adults include:

- |                                 |                                                 |
|---------------------------------|-------------------------------------------------|
| - headache                      | - tingling or numbness in hands and feet        |
| - joint pain                    | - bronchitis                                    |
| - dizziness                     | - inflammation of the sinuses (sinusitis)       |
| - trouble sleeping              | - vomiting                                      |
| - muscle tenderness or weakness | - diarrhea                                      |
| - pain in arms and legs         | - upper respiratory tract infection             |
| - stomach (abdomen) pain        | - cough                                         |
| - shoulder pain                 | - nausea                                        |
| - indigestion                   | - pain in mouth and throat (oropharyngeal pain) |

- People who take Nplate® may have an increased risk of developing new or worsening changes in the bone marrow called "increased reticulins." These changes may improve if you stop taking Nplate®. Your healthcare provider may need to check your bone marrow for this problem during treatment with Nplate®.



**Stay up to date with Nplate®**  
**Scan the QR code to receive additional resources.**

- These are not all the possible side effects of Nplate®. Tell your healthcare provider if you have any side effect that bothers you or that does not go away. For more information, ask your healthcare provider or pharmacist.

- If you have any questions about this information, be sure to discuss with your doctor. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

#### How will I receive Nplate®?

Nplate® is given as an injection under the skin (subcutaneous) one time each week by your healthcare provider. Your healthcare provider will check your platelet count every week and change your dose of Nplate® as needed. This will continue until your healthcare provider decides that your dose of Nplate® can stay the same. After that, you will need to get blood tests every month. When you stop receiving Nplate®, you will need blood tests for at least 2 weeks to check if your platelet count drops too low.

#### APPROVED USE

Nplate® is a prescription medicine used to treat low blood platelet counts (thrombocytopenia) in adults with immune thrombocytopenia (ITP) when certain medicines or surgery to remove your spleen have not worked well enough.

Nplate® is not for use in people with a precancerous condition called myelodysplastic syndrome (MDS), or low platelet count caused by any condition other than immune thrombocytopenia (ITP). Nplate® is only used if your low platelet count and medical condition increase your risk of bleeding. Nplate® is used to try to keep your platelet count about 50,000 per microliter in order to lower the risk for bleeding. Nplate® is not used to make your platelet count normal. It is not known if Nplate® works or if it is safe in people under the age of 1.

Please see Prescribing Information and Medication Guide for more information about Nplate® on [Nplate.com](http://Nplate.com).

