



# ITP CONFERENCE 2022

## THE PREMIER PATIENT EVENT

July 29-31, 2022  
The Westin Seattle

### YOU ARE INVITED TO...

Learn the most up-to-date ITP information

Meet the world's top ITP doctors

Connect with the ITP community

Join us for our 22<sup>nd</sup> national patient  
conference at The Westin Seattle

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# INVITATION TO PARTICIPATE

Celebrating 22 years of patient empowerment, PDSA's ITP Conference 2022 returns to its original format as an in-person and interactive experience, offering ITP patients, caregivers, clinicians, and industry partners the much-anticipated opportunity to gather as a community once again — to reconnect with and learn from one another, and to reap the invaluable benefits of this shared experience.

Described by attendees as a life-changing experience, 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 will 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.

Back by popular demand, the Inquire & Inspire session gives patients and caregivers dedicated time to share their ITP experiences 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 Westin Seattle** in Seattle, WA. Our 22nd annual ITP conference promises to be a weekend of education and inspiration. We look forward to seeing you there!



A handwritten signature in dark blue ink that reads "Caroline Kruse".

Caroline Kruse  
President and CEO

# ABOUT THE SPEAKERS



## **DAVID GEORGE BROOKE - THAT GRATITUDE GUY (KEYNOTE SPEAKER)**

David George Brooke – That Gratitude Guy, has been a speaker, coach, and best-selling author for over 25 years. He is a former Nordstrom store manager and has managed in the corporate world for over 30 years.

Brooke's published works include "That Gratitude Guy's Daily Gratitude Journal", "Monday Morning Minutes: 100 Messages of Gratitude", "Six-Word Lessons to Embrace Gratitude" and a number of other books on gratitude. As a result of his passion for gratitude, he has presented over 750 speeches and workshops in the past eight years, including over 100 Zoom presentations in the last 18 months. He has over 1500 gratitude videos on YouTube, and over 1500 subscribers. Thousands have seen Mr. Brooke's message, and he is now considered a leading authority on how living a life of gratitude can enhance and improve your life, both personally and professionally. He resides in Seattle, Washington.



## **JAMES BUSSEL, MD**

Dr. James Busse is Professor of Pediatrics, Medicine, and Obstetrics at the Weill Medical College of Cornell University in New York City and PDSA Medical Advisor. 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. Busse'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.



## **NICHOLA COOPER, MD**

Dr. Nichola Cooper is a Senior Lecturer and Honorary Consultant Haematologist and at Hammersmith Hospital, Imperial College, London, UK and a PDSA Medical Advisor. She completed her undergraduate degrees at Cambridge University and Barts and the London Hospital Medical College, University of London, UK. During her haematology training, Dr Cooper undertook a research fellowship at Cornell Medical School, New York Presbyterian Hospital, USA with Jim Busse, investigating the clinical and laboratory impact of treatments such as rituximab and anti-D immunoglobulin in patients with ITP. She also studied at Great

Ormond Street Hospital and the Royal Free Hospital, London, where she gained further experience in both paediatric and adult immunodeficiency disorders. Dr. Cooper runs a clinical and laboratory research programme investigating the causes of haematological autoimmunity. She has authored many papers published in international, peer-reviewed journals including Nature Immunology, Blood and the British Journal of Haematology.



**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, Director of Transfusion Services for the University of Washington Medical Center and the Seattle Cancer Care Alliance, and PDSA Medical Advisor.

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 auto-immune thrombocytopenic purpura (ITP).



**CRAIG KESSLER, MD**

Dr. Craig Kessler is professor of Medicine and Pathology and Section Chief of Hematology and PDSA Medical Advisor. He is also Director of the Coagulation Laboratory at Georgetown. A graduate of Tulane School of Medicine, Dr. Kessler received his specialty 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.



**DAVID J. KUTER, MD, DPHIL**

Dr. David Kuter is Chief of Hematology, Massachusetts General Hospital, Boston, Massachusetts and PDSA Medical Advisor. 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.



### **MICHELE P. LAMBERT, MD, MSTR**

Dr. Lambert is an Assistant Professor of Clinical Pediatrics at the Children's Hospital of Philadelphia, Medical Director of the Special Coagulation Laboratory at CHOP, and PDSA Medical Advisor. 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 Master's 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 (USC) Keck School of Medicine, Los Angeles, CA and PDSA Medical Advisor. 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.



### **DIANE J. 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 (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 was a Senior Staff Scientist and Head of the Toronto Platelet Immunobiology Group at the Keenan Research Centre for Biomedical Sciences. He was also a Professor in the Departments of Pharmacology, Medicine and Laboratory Medicine and Pathobiology at the University of Toronto and an Adjunct Scientist with Canadian Blood Services. He joined Lund University in 2016 as a Professor of Transfusion Medicine of St. Michael’s Hospital. Dr. Semple has published over 120 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. Dr. Semple 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, Medical Director of the Bleeding & Clotting Disorders Institute, and PDSA Medical Advisor. 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.

# CONFERENCE AGENDA

## FRIDAY, JULY 29

3:30 – 5:00 PM

**Registration/Exhibits open**

5:00 – 5:15 PM

**Welcome**

5:15 – 6:15 PM

**New insights into what causes ITP  
The phases of ITP: from acute to chronic**

6:15 – 7:00 PM

**Patient Mixer**

7:00 – 8:30 PM

**Inquire & Inspire: patients ask the experts and share personal journeys (small group sessions)**

- **Canadian Patients & Caregivers**
- **For Teens Only**

## SATURDAY, JULY 30

8:00 – 9:00 AM

Registration  
Continental Breakfast  
Exhibits open

9:00 – 10:15 AM

**COVID-19 & ITP update  
Bleeding and clotting issues in ITP**

10:15 – 10:30 AM

Break

10:30 – 11:45 AM

**Inquire & Inspire: patients ask the experts and share personal journeys (small group sessions)**

- **Women & Girls: the unique challenges of living with a bleeding disorder**
- **ITP in Seniors**
- **Teen session: transitioning from high school to college, pediatric hematologist to adult hematologist (for teens and their parents)**

11:45 – 12:00 PM

Break

12:00 – 1:00 PM

**ITP diagnosis & misdiagnosis  
Living with ITP**

1:00 – 2:00 PM

Lunch Break with PDSA Medical Advisors

2:00 – 3:00 PM

**New era of ITP therapy: current ITP treatments, combination treatments and treatments in development  
Genome testing in ITP**

## **SATURDAY, JULY 30 CONTINUED**

3:00 – 3:15 PM	Break
3:15 – 4:30 PM	<b>Concurrent Sessions:</b> <ul style="list-style-type: none"><li>• <b>ITP in Adults: Q&amp;A</b></li><li>• <b>Children with ITP: treatments, school, and sports</b></li></ul>
4:30 – 5:15 PM	<b>ITP and dietary supplements</b>
5:15 – 5:30 PM	<b>Announcements</b>
5:30 – 6:30 PM	Break
6:30 – 7:30 PM	<b>Dinner Program</b>
7:30 – 9:30 PM	<b>Saturday Evening Event</b>

## **SUNDAY, JULY 31**

9:00 – 10:30 AM	Continental Breakfast Support Group Facilitators' Breakfast (pre-registration requested)
10:30 – 11:30 AM	<b>Living with ITP: patients share their stories</b>
11:30 – 11:45 AM	Break
11:45 AM – 12:45 PM	<b>Keynote Address: That Gratitude Guy</b>
12:45 – 1:00 PM	Closing Remarks

### NOTES:

- A separate track for teens and young adults will run Friday and Saturday
- Agenda and speakers subject to change
- Please note that exhibits are only open during session breaks

### *Conference Attendee Feedback*



*I learned many things about ITP, in fact I am about to start a new treatment and feel well informed about it.*

*THANK YOU!! PDSA has made my 8-year journey with ITP an informed one with a knowledge that there are others out there who share and care!*

*We are thankful to everyone at PDSA. Words cannot express how grateful we are to be part of such a wonderful, caring team.*



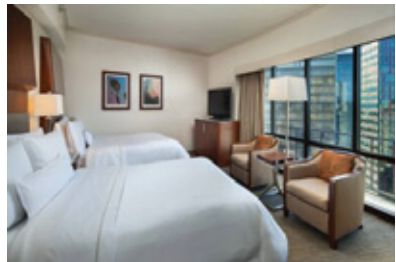




## CONFERENCE LOCATION

All meeting activities will be held at The Westin Seattle. Located just 13 miles from the Seattle-Tacoma International Airport, The Westin Seattle is one of downtown Seattle's most dynamic destinations. The hotel offers spacious hotel rooms and suites with anticipatory service, signature Heavenly® amenities, and stunning views of the Seattle skyline. Seattle's famed Pike Place Market, the Space Needle, Washington State Convention Center, and Lumen Field are nearby, offering ample opportunities for adventure and exploration. Come discover the Emerald City at The Westin Seattle.

If you plan to stay at The Westin Seattle, PDSA is pleased to offer a special conference rate for patients and caregivers of \$159 a night (king or double/double), plus tax. This rate is for 2 adults or a family of 4 with children under age 18. Triple and quad occupancy rates are higher. 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 7, 2022, and is subject to availability. Hotel rooms CANNOT be booked prior to your conference registration.



# SAFETY PLAN

The safety of all attendees and presenters remains our priority. We have designed a comprehensive plan of health and safety protocols that follows current Centers for Disease Control and Prevention (CDC) guidance, the opinions and direction of our Medical Advisors, and the insightful feedback of our patient community.



## VACCINATIONS

Attendees (ages 5 and up) are required to be fully vaccinated against COVID-19, which is defined by the CDC as:

- 2 weeks after the second dose in a 2-dose vaccine series (Pfizer, Moderna or AstraZeneca)
- 2 weeks after a single-dose vaccine (Johnson & Johnson/Janssen vaccine)



## PROOF OF VACCINATION

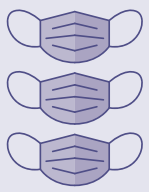
Attendees are required to submit proof of vaccination via Crowdpass/Enterprise by **Friday, July 22, 2022**.

How to enroll with Crowdpass/Enterprise:

- Create a Crowdpass/Enterprise account at [www.crowdpass.co](http://www.crowdpass.co). Here you will input your contact and vaccination information.
- Once your vaccination information has been approved, you will receive a QR code that will be scanned when you come to registration at the conference. You can also print your confirmation.
- This service is completely confidential. Your personal medical information will not be shared nor sold to third parties.
- To upload your vaccination information for PDSA's ITP Conference 2022, please use this link - <https://app.crowdpass.co/test/auth/signin?callbackUrl=app.crowdpass.co/auth/6392>

With Crowdpass/Enterprise, you are always in control of your information. PDSA only receives confirmation that you have completed the requirements and does not have access to your private health data.

If you need additional assistance with your Crowdpass/Enterprise account, contact [support@crowdpass.co](mailto:support@crowdpass.co). You may also contact PDSA's Director of Programs and Events Jody Shy at [jshy@pdsa.org](mailto:jshy@pdsa.org) with any questions.



### **MASK WEARING**

Wearing a protective face mask is required for all attendees (ages 2 and up). Masks must cover both nose and mouth while participating in all conference sessions and events.

Surgical masks will be provided on site. Surgical, N95, and KN95 masks are strongly preferred. Well-fitting cloth masks are acceptable. **Gaiters, bandanas, and masks with exhalation valves will not be accepted.**

Attendees who are not properly masked will be refused admittance and may have their badges revoked.



### **ATTENDANCE PRECAUTIONS**

Do not travel to ITP Conference 2022 if:

- You have been exposed to COVID-19.
- You tested positive for COVID-19 and haven't ended quarantine (even if you are fully vaccinated).
- You are awaiting COVID-19 test results. Should you attempt to travel while awaiting results and your test comes back positive while you are at your destination, you will need to quarantine and postpone your return until it is safe to do so. Your travel companions may need to self-quarantine as well.
- You feel sick or have any symptoms ([www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html](https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html)).

## **MORE INFORMATION**

Visit our website: [www.pdsa.org](http://www.pdsa.org)

Call: (440) 746-9003

Email: [pdsa@pdsa.org](mailto:pdsa@pdsa.org)

# ITP CONFERENCE 2022 REGISTRATION FORM

July 29 – 31 Seattle, WA

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

## 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)

**I have read and acknowledge that I understand and will adhere to the safety protocols in place for this event.**

## 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 preceding 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, 2022

*After June 30, 2022 registration prices will increase.*

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

\*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. All fees less a \$50 administrative charge will be refunded.

## Hotel Reservations

All Conference sessions, meals and receptions will take place at The Westin Seattle. Seattle has been a sought-after location for our attendees so PDSA has secured room rates for patients, caregivers and family attending the conference at \$159 per night (king or double/double). 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.

# REGISTRATION INFORMATION

**SCHOLARSHIPS:** Partial scholarships that cover ITP Conference registration for two and your hotel room plus taxes and fees 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 to [bfoster@pdsa.org](mailto:bfoster@pdsa.org) or via mail to PDSA, 8751 Brecksville Road, Suite 150, Cleveland, OH 44141. **The deadline for scholarship applications is June 30, 2022.**

**Please note:** *Travel costs are **NOT** included in the partial scholarships. Due to the limited number of scholarships available, they will be awarded on a first come, first served basis and preference will be given to first-time conference attendees. You **MUST** be a paid 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. All fees, less a \$50 administrative charge, will be refunded.

**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. Exhibits are only open during session breaks.

**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.

**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).



**Empowering ITP Patients**

8751 Brecksville Rd., Ste. 150  
Cleveland, OH 44141

[www.pdsa.org](http://www.pdsa.org)

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