

# ITP CONFERENCE 2019

— The Premier Patient Event —

## LET YOUR VOICE BE HEARD



Fairmont Washington, D.C.  
Georgetown  
July 26-28, 2019

JOIN US AT OUR 19<sup>TH</sup> NATIONAL PATIENT CONFERENCE

Learn the most up-to-date ITP information

Meet the world's top ITP doctors

Connect with the ITP community



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

*Connecting the global community of patients, caregivers, practitioners and key disease stakeholders to transform the future for people with ITP and other platelet disorders.*



# INVITATION to PARTICIPATE

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

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

The purpose of PFDD meetings is to hear directly from patients, their families, caregivers and patient advocates. The FDA has conducted over 25 disease-specific PFDD meetings to more systematically obtain the patient perspective on specific diseases and their treatments. The FDA recognizes that there are many more disease areas that can be

## 2018 ITP CONFERENCE AT A GLANCE



**265 Attendees**



**Separate Teen/  
Young Adult Track**



**6 Exhibitors**




**12 Speakers**



**Kids Kamp**



**Small group sessions  
with ITP specialists/  
Medical Advisors**



addressed beyond the PFDD meetings planned and conducted by FDA, so they are giving patient advocacy organizations the opportunity to host their own PFDD meetings, with input and guidance from FDA.

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

We have scheduled time with our exhibitors so you can meet directly with the companies who are providing treatments and conducting 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 Fairmont Washington, D.C., Georgetown in Washington, D.C. Our 19th annual ITP conference promises to be a weekend of education and inspiration. We look forward to seeing you there!



Caroline Kruse  
President & CEO



**Celebrated  
PDSA's 20th  
Anniversary**



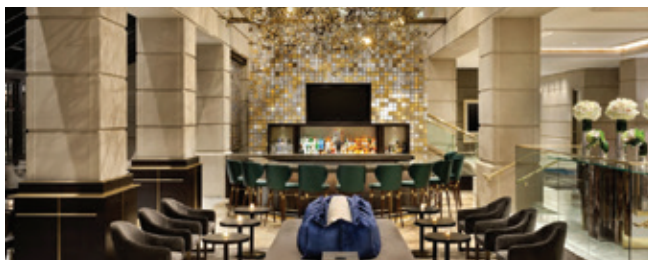




# CONFERENCE LOCATION

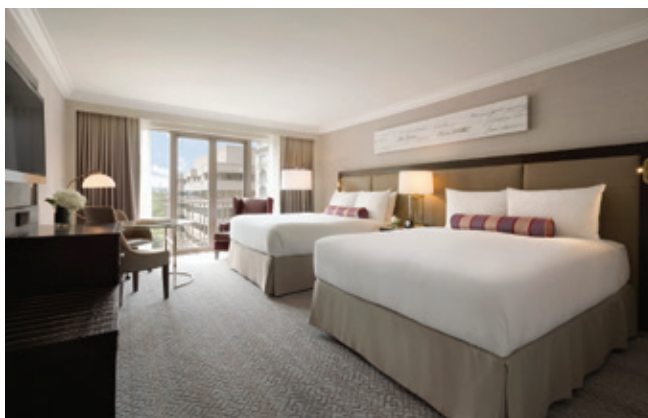
All meeting activities will be held at the Fairmont Washington, D.C., Georgetown. Located in Washington's fashionable West End and adjacent to historic Georgetown, the newly renovated Fairmont Washington, D.C. welcomes guests in capital style. With a sunlit urban courtyard that soothes the spirit, the Fairmont is the perfect hotel for business or leisure travel. A relaxing visit to the hotel's fitness center, indoor pool and serene courtyard provide guests with an array of rejuvenating experiences. The Fairmont Washington, D.C., Georgetown is 5 miles from Ronald Reagan Washington National Airport (DCA), 26 miles from Washington Dulles International Airport (IAD) and 35 miles from Baltimore-Washington International Thurgood Marshall Airport (BWI).





If you plan to stay at the **Fairmont Washington, D.C., Georgetown**, please reserve your room as soon as possible to receive our special conference rate of \$149.00 a night (king or queen/queen), plus tax. **This rate is for 2 adults or a family of 4 with children under age 18. Triple and quad occupancy rate is \$179.00 per night.** This special PDSA rate is also available for conference attendees three days before and three days after the conference. **This special rate applies to reservations that are made by July 3, 2019, as long as rooms at the hotel are available.** We encourage you to make your hotel reservation early to ensure room availability.

Reservations can be made online here: <https://bit.ly/2AAYiym> or by calling **800-441-1414** and referencing the group code **Platelet Disorder Support Association**.



# 2019 CONFERENCE PROGRAM\*

## FRIDAY, JULY 26

### (PATIENT-FOCUSED DRUG DEVELOPMENT MEETING)

9:00 AM – 11:00 AM	Registration
11:00 AM – 11:15 AM	<b>Welcome, Introductions &amp; Opening Remarks</b>
11:15 AM – 11:45 AM	<b>Background on Immune Thrombocytopenia (ITP)</b>
	<b>Topic 1: Effects of ITP that Matter Most to Patients and Caregivers</b>
11:45 AM – 12:15 PM	<b>Panel Discussion on Topic 1 where a panel of patients and caregivers will provide comments</b>
12:15 PM – 1:15 PM	<b>Facilitated Group discussion by patients and patient representatives from the audience will be invited to contribute to the discussion</b>
1:15 PM – 2:00 PM	Lunch
	<b>Topic 2: Patient Perspectives on Current Approaches to Treatments</b>
2:00 PM – 2:30 PM	<b>Panel discussion on Topic 2 where a panel of patients and caregivers will provide comments</b>
2:30 PM – 3:30 PM	<b>Facilitated Group discussion by patients and patient representatives from the audience will be invited to contribute to the discussion</b>
3:30 PM – 3:45 PM	<b>Open Public Comments</b>
3:45 PM – 4:00 PM	Closing Remarks
4:00 PM – 5:00 PM	<b>Patient Mixer</b>

\* A separate track for teens and young adults will run Friday & Saturday.  
Agenda and speakers subject to change.

## MORE INFORMATION



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



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



**Toll-free:  
1-877-Platelet  
(1-877-528-3538)**

*"The conference was the best! I love seeing old friends and making new ones!  
I always look forward to it. Caroline Kruse and her staff do a tremendous job!"  
-Barbara P., 2018 Conference Attendee*



## SATURDAY, JULY 27

8:00 AM – 9:00 AM	Registration / Continental Breakfast / Exhibits open
9:00 AM – 10:15 AM	<b>ITP Treatment Guidelines Update</b>
10:15 AM – 10:30 AM	Break
10:30 AM – 11:30 AM	<b>Inquire &amp; Inspire: patients ask the experts &amp; share personal journeys</b> (small group sessions)
11:30 AM – 11:45 AM	Break
11:45 AM – 12:45 PM	Breakout Sessions <ul style="list-style-type: none"><li>• <b>Canadian Patients &amp; Caregivers</b></li><li>• <b>Children with ITP: treatments, school &amp; sports</b></li><li>• <b>ITP in Adults</b></li></ul>
12:45 PM – 1:45 PM	Lunch Break with PDSA Medical Advisors
1:45 PM – 2:45 PM	<b>Clinical Trials: what's new in ITP</b>
2:45 PM – 3:00 PM	Break
3:00 PM – 4:00 PM	<b>Inquire &amp; Inspire: patients ask the experts &amp; share personal journeys</b> (small group sessions) <ul style="list-style-type: none"><li>• <b>Women &amp; Girls: the unique challenges of living with a bleeding disorder</b></li></ul>
4:00 PM – 4:15 PM	Break
4:15 PM – 5:00 PM	<b>PDSA Patient-Centered Research</b> (two recipients of PDSA research awards will present their research)
5:00 PM – 6:30 PM	Break
6:30 PM – 7:30 PM	Dinner Program
7:45 PM – 10:00 PM	<b>Saturday Evening Moonlight Monument Tour</b>

## SUNDAY, JULY 28

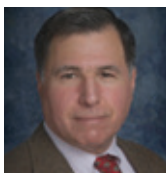
9:00 AM – 10:30 AM	Continental Breakfast Support Group Facilitators' Breakfast (pre-registration requested)
10:30 AM – 11:30 AM	<b>Keynote</b> – TBA
11:30 AM – 11:45 AM	Break
11:45 AM – 12:45 PM	<b>Communicating with Your Doctor</b>
12:45 PM – 1:00 PM	Closing Remarks

# ABOUT the SPEAKERS



**James Bussel, MD** 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.



**Douglas Cines, MD** is a professor of Pathology and Laboratory Medicine at the University of Pennsylvania-Perelman School of Medicine. He received his MD from New York University School of Medicine, his training in internal medicine at the University of North Carolina-Chapel Hill and in hematology-oncology at the


University of Pennsylvania where he has been on the faculty since 1979 and where he has been medical director of the Special Coagulation Laboratory for the PENN Health System for 25 years. He also directs an NIH funded research laboratory investigating immune platelet disorders among other topics. He has been a member of the international working group and international and ASH guidelines committees on ITP.



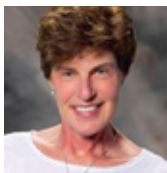
**Nichola Cooper, MD** is a Senior Lecturer and Honorary Consultant Haematologist and at Hammersmith Hospital, Imperial College, London, UK. She completed her undergraduate degrees at Cambridge University and Barts and the London Hospital Medical College, University of London, UK. During her haematology

training, Dr. Cooper undertook a research fellowship at Cornell Medical School, New York Presbyterian Hospital, USA with Jim Bussel, 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** 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.



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

*"Thank you for giving us the chance to not only speak with medical professionals but with others. It was an amazing weekend!"*  
-Winnifred T., 2018 Conference Attendee



**Craig Kessler, MD**, 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, D.C. 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** is Chief of Hematology, Massachusetts General Hospital, Boston, Massachusetts. He earned a research doctorate (DPhil) at Magdalen College of Oxford University and a medical degree at Harvard Medical School. Dr. Kuter is Professor of Medicine at Harvard Medical School. In addition, Dr. Kuter sits on

numerous national and international ITP committees and is board certified in Internal Medicine, Hematology, and Medical Oncology. He has dedicated years of effort to researching coagulopathies, anticoagulation, and platelet disorders. In recent years, Dr. Kuter has conducted groundbreaking research into the development of effective thrombopoietic agents.



**Michele P. Lambert, MD, MTR** 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.

*"Thank you so much! As first timers we thoroughly enjoyed the entire weekend and learned so much! The presenters, venue, food, location, exhibits and of course, celebration party at the Rock and Roll Hall of Fame were all amazing! We hope to see you again." -Julie A., 2018 Conference Attendee*



**Howard A. Liebman, MD** 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.



**John W. Semple, PhD** 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** 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.

# THANK YOU TO OUR 2019 NATIONAL ITP CONFERENCE SPONSORS

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*"What an amazing conference! Loved seeing old friends  
and meeting new friends as well! Thank you all so much!"*  
-Genevieve K., 2018 Conference Attendee

*"We had a blast! Thank you so much, Platelet Disorder Support Association,  
for planning such an amazing weekend. We learned so much.  
Thank you, Allison and the rest of the crew in the Kids Kamp for making  
kids camp so much fun for the littles. Cayden and Cora had a BLAST!"*  
-Jenni K., 2018 Conference Attendee





# ITP CONFERENCE 2019 REGISTRATION FORM

**July 26-28 Washington, D.C.**

**Mail to: PDSA** 8751 Brecksville Road, Suite 150, Cleveland, OH 44141

## **Step I - General Meeting Registration\*** - person attending conference

(See lines for guest names below)

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

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

\_\_\_\_\_  
Address

\_\_\_\_\_  
City ST or Province ZIP Code Country

\_\_\_\_\_  
Phone (H) Phone (Cell) Email

## **Additional guests or family members**

**Please include Name, Address, & Phone number for each additional attendee for their Name Badge**

\_\_\_\_\_  
Guest or family member name Guest or family member name Guest or family member name

\_\_\_\_\_  
Phone Number of Guest Guest Address (if different than above)

\_\_\_\_\_  
City ST or Province ZIP Code Country

☐ I have special dietary needs. Please explain:

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

## **STEP II - Apply for a Partial Scholarship**

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

**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. 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.

### STEP III – 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 Fee 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) \$ \_\_\_\_\_

**Early Registration: Through July 3, 2019** After July 3, 2019, registration fees will increase.

	MEMBER FEE	NON-MEMBER FEE	
Individual	\$140	\$160	\$ _____
Children ages 5-12	\$50	\$60	\$ _____
Children 4 and under	FREE	FREE	\$ <b>FREE</b>
Registration: One Day Pass (Fri/Sat or Sat/Sun)	\$100	\$120	\$ _____
PDSA Circle of Hope Member Registration: 2 complimentary Registrations			\$ <b>FREE*</b>
~or~ PDSA Facilitator Registration: 1 complimentary Registration			\$ <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 (Full payment is due at time of registration)** \$ \_\_\_\_\_

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

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

Card No.: \_\_\_\_\_

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

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

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

### STEP IV – Make Your Hotel Room Reservations

The PDSA discounted room rate is \$149.00/night (king or queen/queen). Reservations must be made by July 3, 2019 in-order to get the PDSA \$149 per night discounted price as long as rooms at the hotel are available. The rate is for 2 adults or a family of 4 with children under 18. Triple and quad occupancy is \$179.00 per night. If you would like to make your reservation directly online, please go to <https://book.passkey.com/event/49819408/owner/56417/home>.

If you would like to contact The Fairmont Hotel Washington, D.C., Georgetown, please call 1-800-441-1414. Please let the representative know the group is Platelet Disorder Support Association.

# REGISTRATION INFORMATION

**SCHOLARSHIPS** Partial scholarships that cover ITP Conference registration for two and your hotel room for 2 nights (Friday and Saturday) are available. Please return your completed registration form, along with a letter describing your diagnosis, your financial need, and the benefit you hope to derive from attending the conference. Information can be returned via email at [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 28, 2019.

Please note: Travel costs are NOT included in the partial scholarship. Due to the limited number of scholarships available, they will be awarded on a first come, first serve basis and preference will be given to first-time conference attendees. You **MUST** be a PDSA member to be eligible for a scholarship. Scholarships are only awarded for full, 3-day conference registrations.

**CANCELLATION POLICY** If you need to cancel your registration for the Conference, you must submit your request to cancel in writing prior to July 3, 2019. All fees less a \$50 administrative charge will be refunded if a written request is received before the July 3rd deadline.

*After July 3, 2019 no refunds will be issued.*

**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.

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