



Platelet  
Disorder  
Support  
Association

Empowering ITP Patients



# 2017 ANNUAL REPORT



Education. Advocacy. Research. Support.

## Mission

The Platelet Disorder Support Association is dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support.

## About PDSA

The Platelet Disorder Support Association is the leading ITP advocacy organization in North America. Each day, PDSA serves the worldwide ITP community of patients, practitioners, caregivers, advocates, and key disease stakeholders, promoting their needs and uniting them on a global level. We build awareness, educate the global community, and provide critical connections and resources that empower patients to take charge of their disease and encourage practitioners to exercise patient-centered medical care.



## From the Executive Director

This year we recognize and celebrate a major milestone in the life of our organization — the Platelet Disorder Support Association's 20th anniversary. But it was in January of last year that PDSA leadership and staff started planning for this major achievement. When we looked at the four pillars of the PDSA mission — education, advocacy, research and support — we realized that while we have made great strides over the past two decades in the areas of patient education, advocacy and support, our involvement in research has historically lagged behind. So in 2017 we prioritized the PDSA research program. Our renewed focus on research is already making a difference in the lives of patients living with ITP.

In February, PDSA launched our ITP Natural History Study Registry. We currently have over 1,000 patients enrolled to date. In June, we advocated for the ITP community on Capitol Hill. In August, we awarded our first-ever PDSA research grants: two \$20,000 pilot grants to investigators conducting original patient-centered research to further understand the pathogenesis and management of primary ITP. In November, we met with the U.S. Food and Drug Administration with the goals of ensuring that the ITP patient voice is included in providing guidance and advancing science, to serve as a comprehensive resource on the patient experience, and provide input and guidance in new drug development research. Closing out 2017, in December PDSA co-organized the ASH (American Society of Hematology) Friday Morning ITP Breakfast, the preeminent scientific ITP meeting, bringing together the top ITP researchers, clinicians, and developers of current and emerging ITP therapies from around the world.

To celebrate PDSA's 20th anniversary and remain focused on our mission to fund the most promising research to find the causes and a cure for ITP, we launched the **PDSA 20/20 Research Campaign: Changing the Lives of ITP Patients**. If PDSA is to continue to underwrite vital ITP research with the potential to transform the lives of ITP patients, we must build and grow our research fund.

As a lead donor to PDSA, we thank you for your past support. Please know that your financial contribution helps PDSA underscore and prioritize patient-centered research. Imagine the impact we could have if every person who has benefited from the work of PDSA chose to also make a gift to our research fund!

There is strength in numbers. If PDSA has touched your life over the past twenty years, we hope you will celebrate our milestone anniversary with us by making a charitable gift to the 20/20 Research Campaign. Together, we can help the best researchers dig deeper to better ITP diagnosis, develop new therapies, and improve patient quality of life.

Sincerely,

A handwritten signature in black ink that reads "Caroline Kruse". The signature is fluid and cursive.

Caroline Kruse  
Executive Director





In 2017, we stepped up our efforts to partner with the scientific community, industry, and government agencies in examining the underlying causes of ITP, developing new treatments, and contributing the patient voice to the regulatory process. By supporting patient-centered research, we will ensure that the patient voice is heard and that patient perspective impacts the research and development of therapies that lessen the burden of living with ITP.

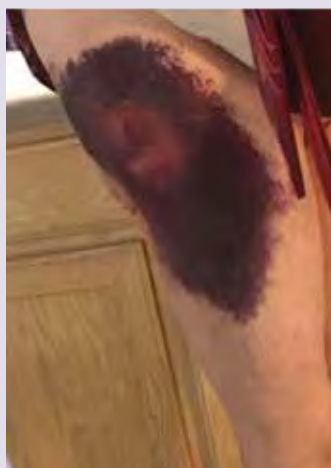


From L-R: FDA Principal Deputy Commissioner Rachel Sherman, FDA Director Wilson Bryan, PDSA Executive Director Caroline Kruse, and moderator Cole Werble, Provision Policy discuss operationalizing patient input into approval decisions at BioPharma Congress III held in Washington, DC on November 14, 2017



## What is ITP?

**Immune thrombocytopenia** or ITP is a rare autoimmune condition that can be as challenging to pronounce as it is to live with. Characterized by low blood platelet counts, you may hear ITP called by its original name of idiopathic thrombocytopenic purpura. Historically, “idiopathic” was used because the cause of the condition was unknown. Today we know ITP is caused by the body’s immune system destroying healthy platelets that leads to easy or excessive bruising and bleeding, in addition to initiating a daily roller coaster of emotions and ongoing medical management.



## PDSA Conquers the Capitol

Together with the American Society of Hematology (ASH) and the Thrombosis and Hemostasis Societies of North America (THSNA), ITP patients, caregivers, and PDSA medical advisors, board members and staff met with members of Congress and legislative aides to share our ITP stories and advocate for our patient community, while opposing the administration's proposed cuts in funding to the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).



PDSA Board Chair Peter Pruitt (L) and ITP Patient Barbara Pruitt (R) meeting with Rep. Ileana Ros-Lehtinen (FL)

*"Your association does great work and research. Your articles provide great resources and knowledge especially to those assisting others with navigating through these uncharted waters and of course insurance requirements. Thank you very much for your ongoing research and studies. Hopefully grant money will come through for you."*

—Vicky



Members of PDSA and THSNA on the steps of the Capitol. (L to R) Caroline Kruse, Joseph Pugliese, Alexandra Kruse, Shannon Carpenter, M.D.



PDSA Executive Director Caroline Kruse moderating the Rare Disease Congressional Caucus on Capitol Hill on March 2, 2017



(L to R) PDSA Medical Advisor James Bussel, M.D., PDSA Director of Marketing Nancy Pothast, Katherine Stark (ASH Staff), Peter Kouides, M.D. (University of Rochester Medical Center), ITP Patient Andrew Avrick

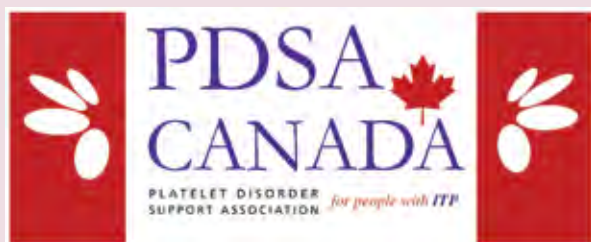


## PDSA staff attended the following meetings:

American Society of Hematology (ASH) 59th Annual Meeting, American Society of Pediatric Hematology/Oncology (ASPHO) 30th Annual Meeting, 22st Congress of the European Hematology Association (EHA), Immunoglobulin National Society (IgNS) National Conference, NORD Rare Diseases & Orphan Products Breakthrough Summit, Plasma Protein Therapeutics Association Stakeholders Meeting, 10th Annual NIH Rare Disease Day



PDSA Executive Director Caroline Kruse, Research Coordinator Alexandra Kruse and Director of Marketing Nancy Potthast greet visitors from around the world at the PDSA booth at ASH 2017 in Atlanta, Georgia



More than **50** people attended PDSA's 1st Regional Meeting in Montreal, Canada



PDSA Executive Director Caroline Kruse (far left) and Director of Marketing Nancy Potthast (far right) with PDSA's Canadian support team, Kristin Hunt and Dale Paynter



(L-R) Drs. Robert Klaassen, Donald Arnold, and James Bussel answer questions

## Advocacy Partnerships

Collaborations are critical to achieving our common mission of improving the lives of the people we serve.

**AARDA – American Autoimmune Related Diseases Association**

**A-Plus – American Plasma Users Coalition**

**ASH – American Society of Hematology**

**CPAG – Coalition of Patient Advocacy Groups**

**FDA Alliance**

**Genetic Alliance**

**IAPO – International Alliance of Patients' Organizations**

**ICON – Pediatric ITP Consortium of North America**

**International ITP Alliance**

**NORD – National Organization for Rare Disorders**

**PBSA – Patients for Biologics Safety & Access**

**PPTA – Plasma Protein Therapeutics Association**

**THSNA – Thrombosis & Hemostasis Societies of North America**

*"What I do want you to know is how much we appreciated the PDSA Conference here in Montreal and congratulate you and your group for all the wonderful work you do."*

– Rena W.

## Notable Moments

# ITP Conference 2017 – A Huge Success with 200 Attendees!



New element this year – Inquire & Inspire small group sessions



Kids Kamp – creative, inspiring and uplifting!

*“Thank you for the scholarship so my sister, Dar, and I could attend the conference this year. The whole PSDA staff did an outstanding job again this year of putting together an informative conference. Thanks to all of you who continue to educate and counsel all of us who are living with ITP. Sunday’s program by Dr. Powers was so inspirational and encouraging.”*

–Donna J.



Dr. Michael Tarantino (L) and the teen group



Dr. Peter Powers, keynote speaker, talks with patients

*“I thoroughly enjoyed my first conference and meeting people who understand was profound for me! Thanks for making it happen each year.”*

–Julie B.



Inaugural ITP Conference Ambassador Program was well-received

## PDSA College Scholarship Program 2017

Four students with ITP were awarded a total of \$3,000.00 in scholarships to help assist with the cost of college.

### Sara Ciesielski

**2017 \$1,500 Scholarship Award Winner**  
Houston, TX – Houston Community College

*“I had a very successful semester in college by getting straight A’s while I pursue a degree in computer science. My health condition has been stable as I continue to receive treatment for ITP. I have grown through this personal challenge by being helpful, loving and kind whenever I can, and try to always have a smile on my face when times get rough. I trust that whatever comes my way in the future, my faith, family, friends, and community will help me to remain strong, positive, and loving to meet those challenges.”*



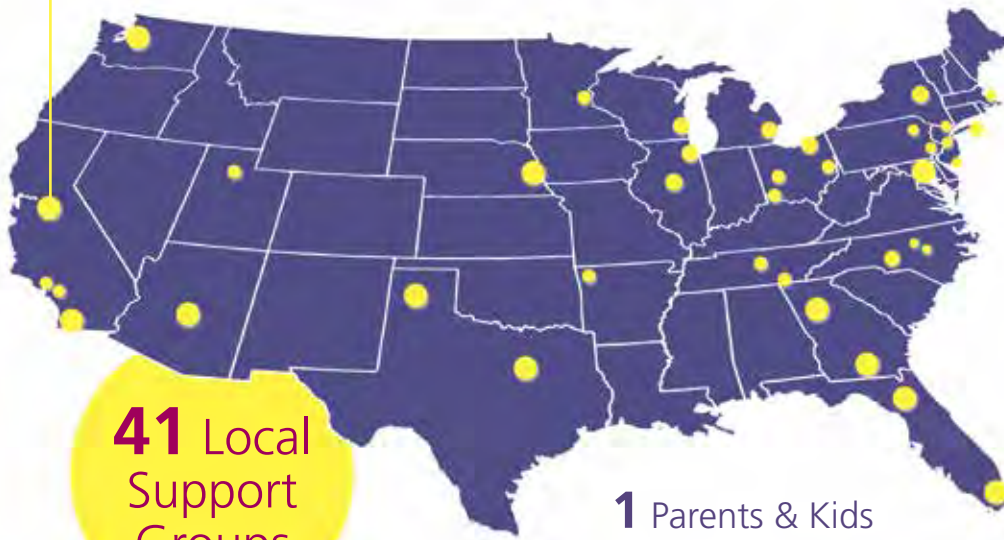


## Sacramento Group

Members of the Sacramento, CA Support Group sport purple at a game with ITP Warrior Josh Phegley (catcher for the Oakland A's).



Logan R. proudly shows off his Buzzy®



**41** Local Support Groups

**1** Parents & Kids Teleconference

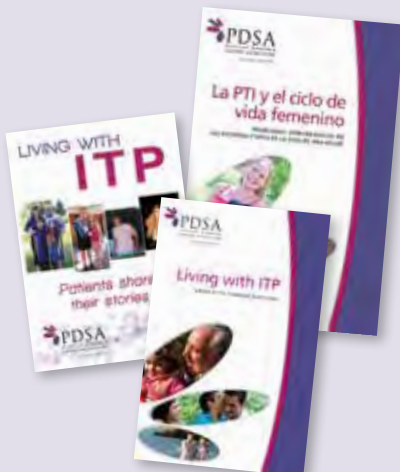
**2** Local Canadian Groups

**1** New Zealand Group

**1** Canadian Teleconference

## Informational Booklets and Numerous Articles

(including Chinese, Dutch, Finnish, French and Spanish versions)



## Quarterly Newsletters

Circle of Hope  
and  
The Platelet News



## Monthly E-Newsletter

PDSA E-News





## Social Networking

 **18,000+**

Facebook Likes & Followers

 **10,000+**

Visit our Facebook page and join our closed group! [/plateletdisorder](#)

 **600+**

Instagram Followers [@PDSA\\_ITP](#)

 **1,200+**

Twitter Followers [@PDSA\\_ITP](#)

 **82,000+**

YouTube Video Views [PDSAorg](#)

 **2,900+**

Vimeo Views

<https://vimeo.com/pdsa>

 **8,900+**

PDSA.org Discussion Group Members

In 2017, the International ITP Alliance and website [www.globalitp.org](http://www.globalitp.org) celebrated its one-year anniversary. The Alliance currently has **28 members** representing **26 countries**.



**pdsa.org**

**60,000**

Unique Visits  
per Month

**90,000**

Total Visits per Month

**4 Million**

Hits per Month



**ITPwalk.org**

**8,000**

Unique Visits  
per Month

**9,000**

Total Visits per Month

**94,000**

Hits per Month



**GlobalITP.org**

**2,800**

Unique Visits  
per Month

**3,700**

Total Visits per Month

**70,000**

Hits per Month

PDSA translated one of our most popular booklets, **Understanding ITP: A Story for Kids about Immune Thrombocytopenia**, into Finnish and Dutch.







## Purple: It's Strong, Bold and All #aboutITP!

In its 8th year, ITP Awareness Month and Sport Purple for Platelets Day continue to grow, inspire and champion the cause. Across the U.S. and around the world, adults, teens, kids and even pets wore bracelets, tee shirts, and sported purple attire, fingernails and hair. Schools, offices and sports teams wore their purple shirts, all to raise public awareness of ITP.







*"pump it up for Platelets!"*

NATIONAL WALK/RUN

**PDSA**

PLATELET DISORDER  
SUPPORT ASSOCIATION



CRANBERRY, PA



BELOIT, WI



AMES, IA



HOUSTON, TX



CHICAGO, IL



ORANGE, CA



GRAND ISLAND, NY



CLEVELAND, OH



BONNE TERRE, MI





## Circle of Hope – Event Organizers

### Pump It Pump It Up For Platelets!

Chicago, IL

**\$18,950.15**

Susan Frank – Organizer

Trish & Paul Santaromana – Organizers

Jennifer Slad – Organizer

Emily Auterson – Team Organizer

Jennifer & Adam Barry – Team Organizers

Mira Hausser – Team Organizer

Alan Levitt – Team Organizer

### Pump It Up For Platelets!

Beloit, WI

**\$10,303.46**

Jennifer & Bob Krueger – Organizers

Sonia & Edward La Vigne – Team

Organizers

### Pump It Up For Platelets!

Orange Co, CA

**\$10,252.00**

Cathy & Raul Aldama – Organizers

Leilani de Castro – Organizer

Aandrea & Billy Hays – Organizers

Melissa Hilsabeck – Organizer

Kelly Torres – Organizer

Angela Racoosin – Team Organizer

### Pump It Up For Platelets!

Cranberry Twp, PA

**\$9,818.35**

Kristen & Steve Tomczak – Organizers

Louann Murtagh – Team Organizer

### Pump It Up For Platelets!

Ames, IA

**\$4,715.00**

Hayley & Nathan Shimanek – Organizers

### Pump It Up For Platelets!

Grand Island, NY

**\$4,190.00**

Cassidy Gallo – Organizer

### Pump It Up For Platelets!

Cleveland, OH

**\$4,128.00**

Caroline & Ken Kruse – Organizers

### Pump It Up For Platelets!

Houston, TX

**\$1,175.00**

Mary John & Manminder (Mindy)

Combaw – Organizers

### NYC Marathon

**\$17,178.87**

Meredith Prescott – Organizer

### Running for Platelets

**\$6,634.90**

Cheri & Derek Zimmerman – Organizers

### Pedal for Platelets!

El Tour de Tucson

**\$2,627.96**

Wanda Gregory – Organizer

Michael Tarantino, MD – Organizer

### Linda's Angels

**\$1,574.00**

Nicole Novello – Organizer

### Canadian Marathon

**\$1,487.86**

Kristin Hunt – Organizer

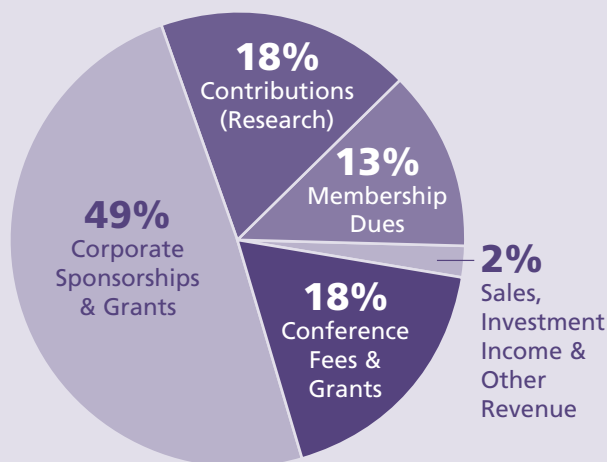


ITP Warrior Meredith Prescott sporting her "Beat ITP" t-shirt triumphantly crosses the finish line at the New York City Marathon



ITP Warrior Kristin Hunt with support from her running buddy and boyfriend, Dave, ran her 4th half-marathon for PDSA

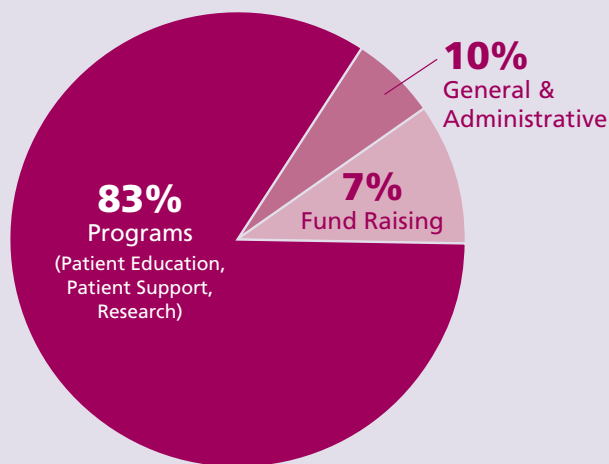
## Income Funding



Contributions (Research)	\$178,438
Corporate Sponsorships & Grants	\$502,509
Conference Fees & Grants	\$186,322
Membership Dues	\$131,221
Sales, Investment Income & Other Revenue	\$17,807

**Total** **\$1,016,297**

## How The Funds Were Used



**\$0.83 of every \$1.00**  
goes directly to programs that support  
and educate the ITP community.

Programs	\$712,075
General & Administrative	\$86,915
Fund Raising	\$56,562
<b>Total</b>	<b>\$855,552</b>

**Net Assets at end of Year (accumulated)** **\$1,305,561**

Each year thousands of individuals, organizations, corporations and foundations help support PDSA through donations of gifts, tributes in memory or honor of family and friends, sponsorships of new programs and special events, and contributions to the annual fund. PDSA receives NO federal funding. Since 1998, it has been the caring members of the ITP community who have given life to PDSA's mission of helping children, adults and families affected by ITP and other platelet disorders. Every gift is important and deeply appreciated. The following list includes gifts received between January 1, 2017 and December 31, 2017.

**PDSA IS PROUD** to be accredited by the Better Business Bureau and to be recognized as a Gold level participant by GuideStar, a standing only 5% of registered charities achieve and a testament to our operating transparency.



### Corporations & Foundations

AMGEN	Novartis
Beloit Health System Foundation	Octapharma
Birny Mason, Jr. Foundation	Patient Centered Outcomes Research Institute (PCORI)
Central Blood Bank	Protalex
Cleveland Clinic Foundation	Regal Beloit Charitable Foundation
CSL Behring	Rigel Pharmaceuticals
Global Genes	Schwab Charitable Fund
Newman's Own Foundation	Shopko Foundation
Ethel & Alexander Nicholason Foundation	

### Matching Gift Companies

The Benevity Community Impact Fund	Hearst
CITGO Petroleum Corporation	The Janus Henderson Foundation
Costco Corporate Office	Peterson Family Foundation
E*Trade Financial Foundation	The Progressive Insurance Foundation
Matching Gift Program	
The GE Foundation	

### Workplace Giving Companies

The Boeing Company	The Progressive Insurance Foundation
IBM Employee Services Center	
iGive	





## Circle of Hope (\$5,000+) Individuals

Madeline & John Hromyak  
Karen & David Imig  
Joan & Richard Jordan  
Louise Kittel Mason  
Barbara & Peter Pruitt, Jr.  
Steven Rodgers  
Cheri & Derek Zimmerman

## Circle of Hope (\$3,000-\$4,999) Individuals

Emily & Kris Kile  
Mary Lou Lyons  
Jacqueline & Bruce Prescott

## Circle of Hope (\$2,000-\$2,999) Individuals

Karen & Adam Avrick  
Kenda & Brian Barnesberger  
Elizabeth & Jerry  
Hoogendoorn  
Sherrill Hudson  
Patricia & C. Ben Nelson  
Joyce & Dale Zimmerman

## Circle of Hope (\$1,000-\$1,999) Individuals

Cindy & J. Phillip Ayliff  
Gigi Barry  
Mary and James Benvenuto

Amita & Ranjive Bhalla  
Charlotte Cunningham-Rundles,  
MD & James Bussel, MD  
Brendan Cameron  
Audrey & Jay Charness  
Rachel & Patrick English  
Kim & Jim Everett  
Robert Feiner  
Allison & Keith Flowers  
Gretchen & Steven Frickx  
Jan & Steve Gardner  
Brenda & Kevin Gubrud  
Kristin Henrikson & Jon Brandt  
Patricia & Bennett Henrikson  
Noelle & Mat Heyman  
Caroline & Ken Kruse  
Irene & David Kuter, MD, DPhil  
David Lihani  
Jenn & Andy Lindal/For the  
Love of Gracie  
Eleonore & Russell McCabe

Katharine McCleary  
The McGuirl Family  
Irma & Daniel Miles  
Stephanie & Mike Moran  
Gary Novello  
Jeanne & Dan Pinnell  
Laura & Neal Prescott  
Shirley & Peter Pruitt, Sr.  
Patricia Pulley  
Virginia Rennie  
Karen Rosenbaum & Ben  
McClinton  
Lisa Scott  
Jody & Jon Shy  
Michael Tarantino, MD  
The Winter Family  
Bonnie & Tom Umhoefer  
Lois Umhoefer

## Benefactors (\$500-\$999)

9 Dots Technology  
Ted Allred  
American Vending Sales  
Archer & Greiner  
Kim & Robert Barber  
Andrew Baysinger  
Bleeding & Clotting  
Disorders Institute  
Melissa & Karen Braverman  
Judith Brennan  
Thomas Buhrfeind  
Carol Stream Dental  
Tania Chiabrera  
Nelson Gaertner  
Kevin Gries  
Amanda Johnson  
Suzanne & Jeff Kerner  
Jennifer Kinon  
Patricia & Dirk Leasure  
June Lee  
Kerry McDermott  
Michael Molnar  
NGS Printing  
Yazdi Parekh  
Diane Paul  
Susan & Dale Paynter  
Stephen Riessen  
Sharon Roberts  
Rosen Family Fund  
San Juan Island School  
District No. 149  
Beth Siegelbaum  
Tri-Beta Biological Honor  
Society  
Universal Display Corp.  
Sonia Vandama  
Neil Weiner  
Becky & Timothy Wirtz

## Associates (\$250-\$499)

Susan & Mark Anderson  
Arlee Ando  
Jerry Baker  
Gerald Barnes

John Benton  
Julie Bosma  
Julie Bremser & Carl Necker  
Brode Lumber Inc.  
Donna Carter  
Amy Chasin  
Children's Community  
Pediatrics – Bass Wolfson  
Pediatrics  
Children's Dental Center of  
Madison, S.C.  
The Children's Rainbow  
Day School, Inc.  
Douglas Cines, MD  
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Michael Cucka  
Daley, Murphy, Wisch &  
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Michael DeMichele, PhD  
Diamond Credit Union  
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Janell & Daniel Eriks  
John Faust  
First Midwest Bank  
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Dee Anne & David Reynolds  
Joan Roane  
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Robert W. Rust  
Marlyce & James Rysavy  
Saint Basil Men  
Terry Schoenherr  
Seneca Valley Jr. Football  
Association & Cheer  
Seneca Valley Soccer  
Association  
Glenda Stormes-Bice

Gail Strachan & David  
Bannon  
Sachiko Terribile  
George H. Tucker, P.A.  
Ronald Virgin  
Theresa & Tony Waxlax  
Daisie Wong  
Margaret Zivelonghi

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Ron Abernethy  
Sandy Adams  
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Valentina Andren  
Anonymous  
Sarah & Craig Antas  
Alexis Antonucci  
Roya Ara  
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 N. Suzanne & Joseph Keiser  
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 Kroeger  
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 Sonia & Edward La Vigne  
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 Adam Lane  
 Mariana Larios  
 Jennifer & Terri Larson  
 Julie LaRue  
 Paul Lasly  
 Suwanna & James Lee  
 Nicole & Tyler Leffel  
 Christine & Terry Lehman

Linda Lehmann  
 John Letang  
 Beverley Letcher  
 Beatrice & Gerald Levine  
 Alan Levitt  
 Jack Levitt  
 Joel Levitt  
 Robert Lewis  
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 William Linkous  
 KeriLynn Loftus, MD  
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 Tod Markelj  
 David Marshall  
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 Tadhg Martin  
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 O'Brien  
 Rosalia Olson  
 Harry Oster  
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 Amit Patel  
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 Nancy Rowe  
 Donna Rumfola  
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 Sisters  
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Gertie Witte  
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Haleigh Wolfe  
David Wolter  
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 Angela Glover

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*"The staff is incredible! I am going to share this information with my hematologist and take better charge of my treatment options. Your hard work and efforts were truly recognized and appreciated! So happy to have the PDSA website for knowledge and support – I don't feel so alone..."*

*"Thank you for all of your hard work. This is such a great opportunity to connect with others, increase our knowledge and renew our hope and commitment to a better quality of life. Thank you! Thank you! Thank you!"*



**PDSA MEDICAL ADVISORS:** (L-R) James Bussel, Michael Tarantino, Donald Arnold, Craig Kessler, Michele Lambert, John Semple, David Kuter, Howard Liebman, Terry Gernsheimer

*"Thank you, doctors and staff, for your time and care in making this information public."*

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## PDSA 20/20 RESEARCH CAMPAIGN: *Changing the Lives* of ITP Patients

### CELEBRATE PDSA'S 20TH ANNIVERSARY!

Last year, PDSA awarded its first-ever research grants: two (2) \$20,000 pilot grants to investigators conducting innovative ITP patient-centered research. We look forward with great anticipation to the impact this funding will have on the lives of patients with ITP. PDSA's Research Program was designed to prioritize patient needs and we believe that the studies we fund will significantly impact ITP diagnosis, therapies, and patient quality of life. But we cannot accomplish this good work alone. Your support is the driving force behind our ability to underwrite much-needed ITP research focused on transforming the lives of ITP patients.

In honor of PDSA's 20th Anniversary, please consider a gift to the 20/20 Research Campaign. Your participation will directly sustain the vital work of researchers focused on developing better treatments, identifying a cause and finding a cure for ITP. Help us raise \$40,000 in charitable donations above and beyond annual membership contributions to sustain and grow PDSA's Research Program.

### There is strength in numbers!

Has PDSA touched your life over the past 20 years? Celebrate this milestone anniversary with a gift to the PDSA 20/20 Research Campaign. Together, we can change the lives of ITP patients.

**Make your gift today and help build PDSA's ITP Research Program.**

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**THANK YOU!**



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