



2019 ANNUAL REPORT

EDUCATION. ADVOCACY. RESEARCH. SUPPORT.



Platelet
Disorder
Support
Association

Empowering ITP Patients



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.



From the President & CEO

I am pleased to share PDSA's 2019 Annual Report with you. The following pages provide an overview of our work throughout the year — highlighting efforts in research, advocacy, education, and support, and recognizing the generosity and impact of people like you who play a vital role in PDSA's continued success.

2019 was a momentous year. As we advanced our mission to enhance the lives of those living with ITP, our work centered on the patient experience. We consistently brought the patient voice to the forefront — concentrating on personal journeys, symptoms, treatment struggles, and fears — to increase awareness and to best articulate the real challenge of living with ITP. The patient voice is central to influencing research, informing the medical community and industry partners, and furthering the development of effective treatments.

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.

We are proud to have brought the ITP patient perspective “to the table” with the FDA through an Externally-led Patient Focused Drug Development (EL-PFDD) Meeting hosted during our annual conference in Washington, D.C. This monumental event was a highlight of the year and a meaningful way to kick off the 2019 ITP Patient Conference, our largest attended to date. PDSA also experienced exponential participation and growth in local support groups, Pump It Up for Platelets events, and ITP Awareness Month activities in 2019. Additionally, we were honored to be recognized by NORD (National Organization for Rare Disorders) as the recipient of the Abbey S. Myers Leadership Award for patient advocacy — a meaningful acknowledgement of our mission and efforts on behalf of patients with ITP.

As we build on the great momentum established in 2019, PDSA's commitment to patient-centered ITP research remains a priority. Our Research Fund continues to grow, which gives us the opportunity to encourage and underwrite new studies focused on improving the patient experience — research that directly addresses patient needs and will lead to new treatment options and better outcomes.

The financial support of our members and donors — toward our daily work and our research program — gives strength and focus to our efforts, allowing us to maintain the impact we have created in serving the ITP patient community. It is my honor to recognize you and the invaluable support you have provided to PDSA. I hope you take pride in knowing that your personal efforts and contributions have served to fuel our mission and the fight against ITP. We could not do this without you.

Sincerely,

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

Caroline Kruse
President & CEO

PDSA BY THE NUMBERS

21 Years

of serving and giving voice to the ITP patient community



1st ever Externally-led Patient Focused Drug Development meeting on ITP,

giving our patient community the opportunity to increase awareness and present their experiences with ITP to the U.S. Food and Drug Administration

3 Websites

PDSA.org
ITPwalk.org
GlobalITP.org



More than **1,100** pages of web content for ITP patients

75,000+ total visitors to our websites each month

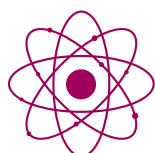
2,093 Members and Donors

whose charitable gifts allow PDSA to fulfill its mission



92 *The Circle of HOPE*
\$1,000+ Circle of Hope Donors providing leadership support to all of PDSA's efforts

5 \$20,000 Research Grants



were awarded to fund original patient-centered ITP research, increasing our research funding impact to a total of 7 grants and \$140,000 in funding

54 Patient Support Groups

Sustained by ITP patients, PDSA's support groups have expanded beyond the U.S. to include Canada and New Zealand



1,005 patients are enrolled in PDSA's ITP Natural History Study Registry

15 Medical Advisors

PDSA's Medical Advisory Board includes internationally renowned clinicians and researchers, all ITP specialists



102 Children with ITP are members of the Poke-R Club,

designed to ease the fear of injections or "needle phobia" that often results from blood draws and treatments



PDSA celebrated its 19th Annual ITP Patient Conference in Washington, D.C. with **315 attendees**, the largest attendance to date



200+ Awareness Events held nationwide



"pump it up for Platelets!"

NATIONAL WALK/RUN

PDSA

9 Pump It Up for Platelets! Walk/Run events across the U.S. and Canada

1,100+ Walk/Run fundraiser participants

\$214,000+ raised for PDSA programs and research

11 Informational booklets

on ITP for adults, teens, children and women translated into multiple languages

PDSA spearheads the **International ITP Alliance** which includes

33 delegates from 29 member countries

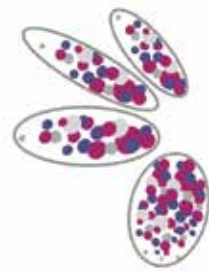


11 Advocacy Partners

with whom we collaborate to achieve our common mission of improving the lives of the people we serve

5 full-time staff / 4 part-time staff

A small but mighty team of individuals dedicated to serving the ITP patient community. We're here for you!



RESEARCH *at* PDSA

The key to unlocking a cure

www.PDSA.org

PDSA continues to lead the way in ITP research by engaging with the scientific community, industry partners, and government agencies to further examine the underlying causes of ITP, develop new treatments, and contribute the patient voice to the regulatory process. Our leadership continues to convene with the U.S. Food and Drug Administration, the American Society of Hematology (ASH), and the European Hematology Association (EHA) to monitor the ongoing progress of relevant research studies and initiatives. Each year, PDSA hosts the ASH Friday Morning ITP Breakfast, where global ITP investigators present their leading-edge ITP research. PDSA also partners with ICON (the Pediatric ITP Consortium of North America), a collaborative research effort of 49 pediatric hematologist centers committed to advancing the care of children with immune thrombocytopenia (ITP). Our commitment to patient-centered research keeps the ITP patient perspective at the center of the research process – ensuring outcomes that will directly impact ITP patient quality of life.

The Barbara and Peter T. Pruitt Jr. ITP Research Awards

Each year, the PDSA Research Program grants up to three \$20,000 awards to investigators conducting innovative ITP patient-centered studies. These awards are given in honor of longstanding PDSA champions Barbara and Peter Pruitt. Funding of the PDSA Research Program is provided through the charitable support of the 20/20 ITP Research Campaign.

2018/2019 RESEARCH AWARDS

Project Title:

The Role of the Gut Microbiome in the Pathogenesis of ITP

Investigator: Joseph Oved, MD

Institution: The Children's Hospital of Philadelphia

Project Title:

Decision Aid to Support Shared Decision Making in Pediatric Refractory Immune Thrombocytopenia

Investigator: Cindy Neunert, MD, MSCS

Institution: Columbia University Medical Center

Project Title:

Association of Platelet Parameters and Subpopulations Identified by High Dimensional Mass Cytometric Analysis of Platelets with Bleeding Severity in Pediatric patients with Immune Thrombocytopenia

Investigator: A.L. "Larry" Frelinger III, Ph.D.

Institution: Boston Children's Hospital

Project Title:

Development of New Diagnostic Tests to Categorize Different Subtypes of Immune Thrombocytopenia (ITP)

Investigator: Ishac Nazy, Ph.D.

Institution: McMaster University



PDSA Patient-Centered Research Award Recipient, Cindy Neunert, MD presents a study update.

Project Title:

Role of Platelet Glycosylation on Platelet Function and Immune Response in Immune Thrombocytopenia Patients

Investigator: Nora Butta, MD

Institution: Hospital Universitario La-Paz



PDSA hosted the annual ITP Breakfast Meeting at the 61st American Society of Hematology (ASH) Annual Meeting held in December 2019.

Coordinated by PDSA and four of its Medical Advisors, Dr. James Bussel, Dr. Nichola Cooper, Dr. Michelle Lambert and Dr. John Semple, 13 hematology experts presented their leading-edge ITP research to the 140+ ITP researchers, clinicians, and industry representatives in attendance at this prominent meeting.



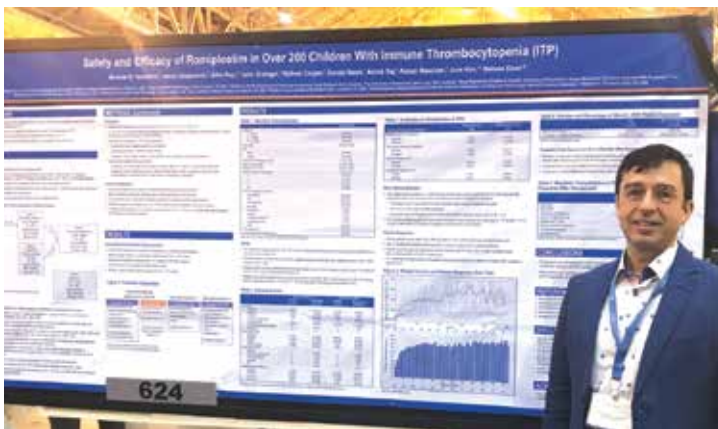
ASH Breakfast: More than 140 ITP researchers, clinicians, industry representatives, along with PDSA staff attended the ITP Breakfast Meeting.



PDSA Medical Advisor James Bussel, MD welcomed attendees to the ASH ITP Breakfast.



Hematologist Ilene Weitz, MD with PDSA Medical Advisor (and husband) Howard Liebman, MD stopped by the PDSA booth in the Exhibit Hall.



PDSA Medical Advisor Michael Tarantino, MD presented his research at the American Society of Pediatric Hematology/Oncology (ASPHO).



PDSA Research Coordinator Alexandra Kruse and Medical Advisor James Bussel, MD in the poster hall at the European Hematology Association Congress in Amsterdam. Both Alexandra and Dr. Bussel presented ITP research poster abstracts.



Pediatric Hematologist Professor Paul Imbach from the University of Basel, Switzerland talks with PDSA President & CEO Caroline Kruse and Director of Marketing Nancy Potthast about their poster "Mental Health and Treatment in Patients with Immune Thrombocytopenia (ITP): Data from the Platelet Disorder Support Association (PDSA) Registry." The research found that patient-reported levels of anxiety and fatigue were overall quite high yet did not differ between treatment type, highlighting the need to recognize that ITP does not just affect patients physically.

PDSA recognized by The National Organization for Rare Disorders (NORD)



On June 22, 2019, PDSA received the Abbey S. Myers Leadership Award at NASA Space Station in Houston, Texas. The National Organization for Rare Disorders (NORD) selected PDSA for this honor out of over 280 member organizations representing more than 7,000 rare disease patients.

The Rare Impact Awards Gala was attended by more than 550 guests. PDSA staff was joined by our Houston support group facilitators Sara and Mark Ciesielski, Houston walk/run organizers Manminder (Mindy) Combaw and Mary John, and hematologists Jenny Despotovic, DO and Amanda Grimes, MD, from Texas Children's Hospital. The event was hosted by Olympic gold medalist Mary Lou Retton.

"Some things may seem impossible, like winning a gold medal or exploring outer space," said Retton, who won five gold medals at the 1984 Summer Olympics. "But tonight, we honor the hard work of everyone in this room, people who beat the odds to live their best lives every single day. If there was a gold medal for selfless service, it would certainly go to them."



PDSA staff (L to R) Brenda Foster, Alexandra Kruse, Caroline Kruse, Jody Shy and Nancy Potthast.



Retired astronaut Kenneth Cameron, Olympic gymnast Mary Lou Retton, PDSA President & CEO Caroline Kruse and Research Coordinator Alexandra Kruse.

PDSA hosts Inspiring and Educational Weekend in Canada

52 Canadian ITP patients, caregivers, pharmaceutical representatives, hematologists and PDSA staff and volunteers gathered for PDSA's second Canadian Regional Meeting in London, Ontario.



Dale Paynter (L) with PDSA Medical Advisor, Dr. Donald Arnold (R) break for the camera during the second PDSA Canada ITP Regional Meeting held on Sunday, April 28, 2019 at Winderemere Manor in London, Ontario.

The International ITP Alliance

welcomed the ITP Israel patient support group in 2019, increasing its growing list of intercontinental partners to 29.



Eighteen delegates from twelve countries! Representatives from China, Netherlands, Israel, Argentina, New Zealand, Denmark, Brazil, United Kingdom, United States, Australia, Italy and Finland hold the flags of their respective countries at the International ITP Alliance Symposium on July 25th.

PDSA Presentations:

- PDSA Medical Advisor Donald Arnold, MDCM, MSc, FRCP(C) from McMaster University in Hamilton, Canada presented the program "What's New in ITP Research and How Does That Affect Me?" at PDSA's Second Annual Canadian Regional Meeting in April 2019.
- PDSA Medical Advisor Michael Tarantino, MD presented his research at the American Society of Pediatric Hematology/Oncology (ASPHO) Conference in May 2019.
- PDSA Research Coordinator Alexandra Kruse and Medical Advisory James Bussel, MD presented poster abstracts at the 24th Congress of the European Hematology Association (EHA) in Amsterdam in June 2019.
- PDSA President & CEO Caroline Kruse and Director of Marketing Nancy Potthast presented their poster abstract "Quality of Life and Demographics of Patients with Immune Thrombocytopenia (ITP): Data From the Platelet Disorder Support Association (PDSA) Registry" at the National Organization for Rare Disorders' (NORD) Rare Diseases & Orphan Products Breakthrough Summit in Washington, D.C. in October 2019.
- PDSA President & CEO Caroline Kruse participated in a panel discussion on "Engaging Federal Partners: Opportunities through the FDA and PCORI" at the IAMRARE Registry Users Meeting in Washington, D.C. in October 2019.
- PDSA President & CEO Caroline Kruse presented a short program on PDSA services and programs at the 3rd Annual Canadian Conference on Immune Thrombocytopenia Purpura (ITP) in Toronto, Canada in October 2019.
- PDSA President & CEO Caroline Kruse and Director of Marketing Nancy Potthast presented a poster abstract at the 61st American Society of Hematology (ASH) Annual Meeting on "Mental Health and Treatment in Patients with Immune Thrombocytopenia (ITP): Data from the Platelet Disorder Support Association (PDSA) Registry."



Tongfei Meng, Founder of ITP Home in China, takes part in the EL-PFDD meeting on July 26th.



PDSA was well-represented at the ICIS Meeting with eight of our medical advisors in attendance. (L to R) Diane Nugent, MD, PDSA President & CEO Caroline Kruse, Michele Lambert, MD, Douglas Cines, MD, John Semple, PhD, Terry Gernsheimer, MD, Nichola Cooper, MD, Howard Liebman, MD (missing, James Bussel, MD).



PDSA President & CEO Caroline Kruse presenting at the IAMRARE Registry Users meeting.



PDSA President & CEO Caroline Kruse with ITP Patient Gail Strachen from Toronto, Canada.

Meetings Attended by PDSA:

- American Society of Pediatric Hematology Oncology (ASPHO) Conference
- American Society of Hematology (ASH) 60th Annual Meeting
- 24th Congress of the European Hematology Association (EHA)
- 3rd International ITP Alliance Symposium
- NORD 2019 Rare Diseases & Orphan Products Breakthrough Summit
- 3rd Annual Canadian Conference on Immune Thrombocytopenia Purpura (ITP)
- Intercontinental Cooperative ITP Study Group (ICIS) 6th Expert Meeting



PDSA President & CEO Caroline Kruse (L) and Director of Marketing Nancy Potthast (R) discuss their poster abstract "Quality of Life and Demographics of Patients with Immune Thrombocytopenia (ITP); Data From the Platelet Disorder Support Association (PDSA) Patient Registry" with an attendee at the NORD Summit.

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

NORD – National Organization for Rare Disorders

PPTA – Plasma Protein Therapeutics Association

THSNA – Thrombosis & Hemostasis Societies of North America

The ITP Patient Voice Takes Center Stage at the 2019 ITP Patient Conference.

The 2019 ITP Patient Conference was an historic event for the ITP patient community. PDSA hosted its largest conference to date, with 315 attendees, the first Externally-led Patient-Focused Drug Development (EL-PFDD) Meeting on ITP, and 18 members of the International ITP Alliance.



The *first of its kind* to ever be held for ITP, the Platelet Disorder Support Association's Externally-led Patient Focused Drug Development (EL-PFDD) meeting was a groundbreaking event which presented the opportunity for our community to increase awareness and educate the U.S. Food and Drug Administration (FDA) on the real challenges of living with ITP. According to the FDA, "The patient perspective is critical in helping the FDA understand the context in which regulatory decisions are made for new drugs. PFDD meetings give FDA and other key stakeholders, including medical product developers, health care providers, and federal partners, an important opportunity to hear directly from patients, their families, caregivers, and patient advocates about the symptoms that matter most to them, the impact the disease has on patients' daily lives, and patients' experiences with currently available treatments. This input can inform FDA's decisions and oversight both during drug development and during our review of a marketing application."

PDSA enlisted the participation of eight ITP patients to participate in two panel discussions for this landmark meeting. As experts in what it is really like to live with this condition, each patient talked about their individual journey, sharing detailed information on their symptoms and the burden of living with ITP, the impact of treatments they have tried, and their side effects. Additionally, all patients and caregivers attending the meeting had the opportunity to join in the discussion, providing more data on the daily impact of an ITP diagnosis. The tone of this important meeting was like none seen before at our ITP Conference and, while many aspects of the personal journeys were difficult to hear, they were exactly what the FDA needs to be aware of: the unseen bruises of ITP.

We are indebted to those who had the courage to publicly bare their deeply personal challenges to help break down the barriers and transform the future for ITP. PDSA was proud to have compiled and published a *Voice of the Patient* report for the FDA which summarized the perspectives of these brave ITP patients and caregivers.



The Kids Kamp strikes a pose!



Inquire & Inspire: Patients, caregivers and medical experts gather to share insights, spark discovery and influence better outcomes for people with immune thrombocytopenia.



PDSA President & CEO Caroline Kruse welcomed U.S. Food and Drug Administration Division Director, Division of Hematology, Ann Farrell, MD, for the EL-PFDD meeting.

"Thank you, I learned so much!"

— Phyllis C.

"Deepest and most sincere thanks to all the PDSA personnel and organizers. Hats off to Nancy, Caroline and Jody for being so friendly, respectful and willing to listen and help – you and the PDSA help me see ITP with different eyes and hopefully train me to do the same for others in Argentina. Huge hugs!"

— Ruben D.

"A wonderful conference - I enjoyed having the 3 days and I liked the way the first day started with the panel of ITP patients' experience."

— Patricia C.

"The amount of effort necessary to coordinate, plan and implement this program is gargantuan. 2019 conference delivered! PDSA has set the bar very high again! Time and time again, the PDSA conference exceeds my (and our) expectations for imparting knowledge to participants and this year was truly an exemplary experience. Thank you for another wonderful conference."

— Madonna P.



(L-R) David Kuter, MD, DPhil; Craig Kessler, MD; Howard Liebman, MD; John Semple, PhD and Nichola Cooper, MD answer questions from patients and caregivers after presenting "ITP in Adults."



Our roots run deep - PDSA grassroots volunteers gather for the largest Support Group Facilitators Workshop ever – 31 in attendance!

Education & Support

PDSA is dedicated to supporting ongoing awareness and advocacy by encouraging a growing community of ITP Ambassadors for change. Local support groups continue to be a popular and useful tool for ITP patients and loved ones – and our support group family continues to grow!



49 Local Support Groups

2

Canadian Groups
Ottawa, Ontario,
Waterloo-Wellington/
Greater Toronto,
Ontario

1

New Zealand Group

1

Canadian Teleconference Group

1

United States Parents & Kids Teleconference Group



PDSA's ITP Poke-R Club for Kids program welcomed **23 new members** in 2019, serving a total of **107 children**, ages 2 to 17, from **30 states**, **2 provinces** and **2 countries!**



"Thank you, I think this will help tremendously!"
– Linh L., mom of Ava L.

"From the depth of my soul, thank you and your coworkers at PDSA for creating a club like this. The support offered on this site and through this club is indispensable. My sincere thanks."

– Jackie F., mom of Louis F.

"Thank you for this wonderful opportunity and organization. It has sure made a difference in our lives!"

– Teresa C., mom of Thomas C.

2019 PDSA College Scholarship Winners!

\$1,500 RECIPIENT

Luci Takas, Hamburg, NY
Daemen College



"I learned that I am capable of facing adversity with great courage. While I was in the hospital I learned that it is best to stay focused on the immediate challenge, one obstacle at a time. I learned that having a plan and focusing on one task at a time makes overwhelming problems manageable. While facing adversity I learned that I have the strength to remain calm in the face of danger. I am able to think logically and maintain faith in my doctors that are working to find me the best line of treatment. Challenges have the power to inspire growth or defeat in a person. I believe that I have grown through my crisis and am stronger than before."

\$750 RECIPIENT

Emmelee Newhouse, Hurricane, WV
Marshall University



"Although originally planning a career in speech pathology, my diagnosis of ITP has caused me to reconsider and now reach for a medical degree. I feel that the experiences I am facing will help me to become a thorough, thoughtful and successful physician. I am so appreciative of the help that I have received, and I want to help others in the same way. I have found the dedication and determination needed to be successful in overcoming the obstacles I have faced, and I am ready for the challenges that medical school will hold."

\$250 BOOK AWARD RECIPIENTS



Caroline Emerson,
Moore, SC
Clemson University
Calhoun
Honors College

"I am so excited to continue challenging myself, and I hope to use my platelet disorder as a way to inspire others."



Jack Kerr,
Gambrills, MD
Furman University

"... Keeping a positive attitude has made my journey much easier to deal with and keeps me moving forward towards my goals."



Colin Roberts,
Cedarhurst, NY
Louisiana State
University

"...As I overcame each obstacle, I gained more strength. Now, I not only have the strength to get by, I am demonstrating that I possess the strength to thrive..."

"Sixteen years ago my daughter was diagnosed with and successfully treated for ITP. Her platelet count has been robust since then, but other autoimmune-induced diseases have presented. I am grateful that PDSA was a resource for us all those years ago."

—Tammy W.

"I feel so thankful I found a group like this. People don't tend to understand what I am going through because they don't even know what I am talking about. I'm just sad there are so many of us. I will keep you all in my prayers."

—Danae M.

PDSA PUBLICATIONS

Informational Booklets, Articles,
Circle of Hope Quarterly Newsletter,
The Platelet News Quarterly Magazine
and Monthly E-Newsletter



Social Networking

 **26,503+**
Facebook Likes & Followers

 **1,323+**
Instagram Followers @PDSA_ITP

 **1,445+**
Twitter Followers @PDSA_ITP

 **98,529+**
YouTube Video Views PDSAorg

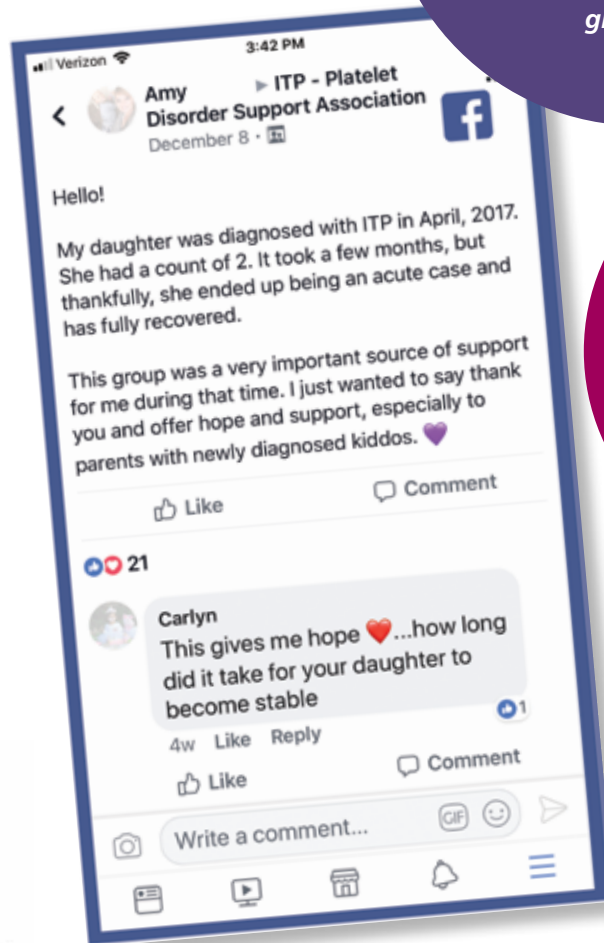
 **12,350+**
PDSA.org Discussion Group Members



"Where would we be without PDSA and pdsa.org? Still groping in the darkness alone as I was before that first click on the website soon after diagnosis."
— Mary I.

"My 12-year-old son was diagnosed with ITP 3 months ago. The PDSA website provided me with tremendous information regarding this rare disease. I cannot imagine how we could survive this horrible journey without help from this website and discussion groups."
— TH

"I feel so much better about my future health after visiting the PDSA website, joining this group and attending the conference. Thank goodness that the research continues!!!"
— Penny H.



pdsa.org

40,000
Unique Visits
per Month

65,000+
Total Visits per Month



ITPwalk.org

1,000
Unique Visits
per Month

2,500+
Total Visits per Month



GlobalITP.org

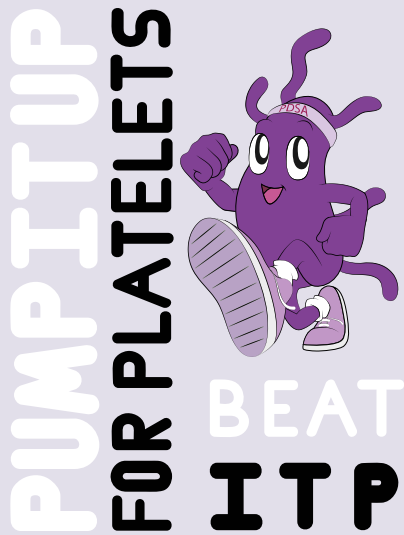
5,000
Unique Visits
per Month

7,000+
Total Visits per Month

Sport Purple for Platelets Day

September is ITP Awareness Month, a time when we mobilize and focus our efforts to shed additional light on ITP and to observe the ongoing courage of ITP Warriors around the world. The last Friday of each September is celebrated as Sport Purple for Platelets Day, a culminating event designed to bring greater awareness to ITP and those living with this rare platelet disorder. Across the country and around the world, adults, teens, children, and their pets sported purple and took to social media to show their platelet pride. Schools, businesses, and sports teams all got in on the action – adding a splash of purple, and a whole lot of awareness!





LONDON, ON



BELOIT, WI



AMES, IA



ORANGE, CA



ATLANTIC, IA



CRANBERRY TWP., PA



SADDLE BROOK, NJ



CLEVELAND, OH



SOUTH SAN FRANCISCO, CA

Circle of Hope – Event Organizers

Pump It Up For Platelets!

Beloit, WI

\$23,858

Jennifer & Bob Krueger, Organizers
Angie & Alan Levitt, Team Organizers

Pump It Up For Platelets!

London, ON

\$13,526

Jennifer & Luigi DiRaimo, Organizers
Julie & Paul Agius, Team Organizers
Samantha Colaiacovo, Team Organizer

Pump It Up For Platelets!

Orange County, CA

\$8,390

Cathy & Raul Aldama, Organizers
Leilani de Castro, Organizer
Melissa Hilsabeck, Organizer
Kelly Torres, Organizer

Pump It Up For Platelets!

South San Francisco, CA

\$6,015

Rigel Pharmaceuticals, Organizers

Pump It Up For Platelets!

Cranberry Twp, PA

\$5,345

Kristen & Steve Tomczak, Organizers
Louann Murtagh, Team Organizer

Pump It Up For Platelets!

Saddle Brook, NJ

\$5,085

Emmerson Winnie, Organizer
John Klein, Team Organizer

Pump It Up For Platelets!

Cleveland, OH

\$5,020

Caroline & Ken Kruse, Organizers
Tracey Parker, Team Organizer

Pump It Up For Platelets!

Ames, IA

\$4,156

Hayley & Nathan Shimanek, Organizers

Pump It Up For Platelets!

Atlantic, IA

\$4,155

Jordan & John Lawson, Organizers

Facebook Fundraisers

\$20,530

Google Fundraiser

\$3,990

Karin Magnuson, Organizer

Zimmerman Fundraisers

\$20,985

Cheri & Derek Zimmerman, Organizers

Sebastian Hoefft Fundraiser

\$1,095

Lindsey Hoefft, Organizer

Rigel ASCO Fundraiser

\$7,500

Rigel Pharmaceuticals, Organizers

Pizza for Platelets

\$1,456

Veronica & Desie Fernandez, Organizers

Mira Hausser Fundraisers

\$1,433

Mira & Jim Hausser, Organizers

Jordan Tutoring Fundraiser

\$1,770

Joan Jordan, Organizer

Platelet for Platelets

\$1,000

Patricia & Robert Monigle, Organizers

"I always recommend that newly diagnosed people go to the PDSA conference or attend a support group meeting so that they can feel the way I did when I actually met someone in person with ITP. It's life changing."

– Trish S.



Photo Credit: Michael Simon / Startraks Photo

Derek Hough flossing with Cayden Krueger.



Elle A. raising awareness and funds for PDSA at her lemonade stand.

Contributions in 2019

It is through the thoughtful generosity of so many that PDSA is able to fulfill its mission of enhancing the lives of people with ITP and other platelet disorders through education, advocacy, research and support. Each year, thousands of individuals, organizations, corporations, and foundations provide meaningful support through charitable gifts, membership, tributes in memory or honor of family and friends, sponsorships of programs, and special events.

Every gift is important and truly appreciated. The following lists recognize those who stepped forward to support our efforts in 2019.

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

AmazonSmile Foundation
AMGEN
Argenx US Inc.
CSL Behring Biotherapies for Life
Dova Pharmaceuticals
Fidelity Charitable Gift Fund
Trevor Frederickson Memorial Fund
Kezar Life Sciences
Colleen O'Hara & Doug Mashkuri Charitable Fund
Merck Foundation
Momenta Pharmaceuticals, Inc.
Ethel & Alexander Nichoson Foundation
Novartis Pharmaceuticals, Inc.
Novartis Pharmaceuticals Canada Inc.
Octapharma
Pantherx Specialty LLC
Pfizer
Pledgeling Foundation
Principia Biopharma
Promosis Inc.
Regal Beloit Charitable Foundation
Rigel Pharmaceuticals, Inc.
Marshall E. Rinker, Sr. Foundation, Inc.
Sanofi Pharmaceuticals
Schneider Electric North America Foundation
Schwab Charitable Fund
Karen Toffler Charitable Trust
UCB Pharmaceuticals, Inc.
US Cellular

Matching Gift Companies

The Benevity Community Impact Fund
Google Matching Gifts Program
The Janus Henderson Foundation
PayPal Giving Fund
Pfizer Foundation Matching Gifts Program

Workplace Giving Companies

Amgen Foundation Staff Giving Programs
AT&T Employee Giving Campaign
iGive
Progressive Insurance Foundation



INDIVIDUAL DONORS

Circle of Hope (\$20,000+)

Katharine McCleary
David Rinker

Circle of Hope (\$10,000-\$19,999)

Joan & Richard Jordan
Mary Lou Lyons
Steven Rodgers

Circle of Hope (\$5,000-\$9,999)

David Lihani
Cheri & Derek Zimmerman
Joyce & Dale Zimmerman

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

Madeline & John Hromyak
Barbara & Peter Pruitt, Jr.
Janeen & Robert Theobald

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

Charlotte Cunningham-Rundles, MD
& James Bussel, MD
Sherrill Hudson
Emily & Kris Kile
Irene & David Kuter, MD, DPhil
Jenn & Andy Lindal/For the Love of Gracie
John Stevenson
Theresa & Tony Waxlax

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

Anonymous
Susan & John Atkinson
Gigi Barry
Mary & James Benvenuto
Amita & Ranjiva Bhalla
Brendan Cameron
Druanne Davies
Kim & Jim Everett
Robert Feiner
Jan & Steve Gardner
Barbara Genen
Jen & Benjamin Grimes
Kim & Rodney Hall
Kristin Henrikson & Jon Brandt
Patricia & Bennett Henrikson
Noelle & Mat Heyman
Karen & David Imig
Jerry Jones
Caroline & Ken Kruse
Louise Kittel Mason
Janet & William McAllister
The McGuirl Family
Irma & Daniel Miles
Stephanie & Mike Moran
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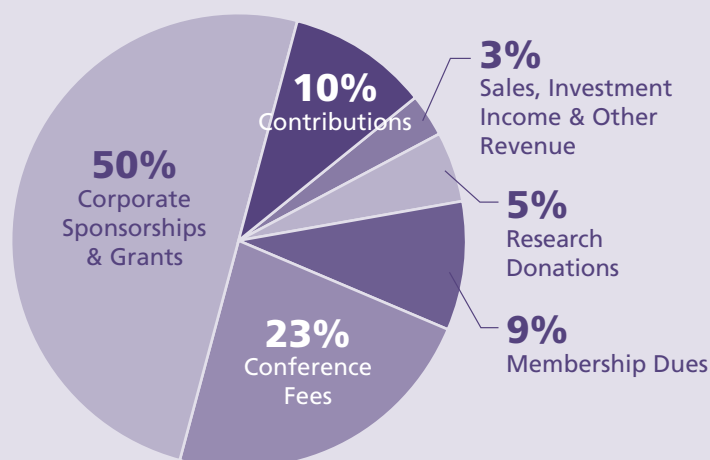
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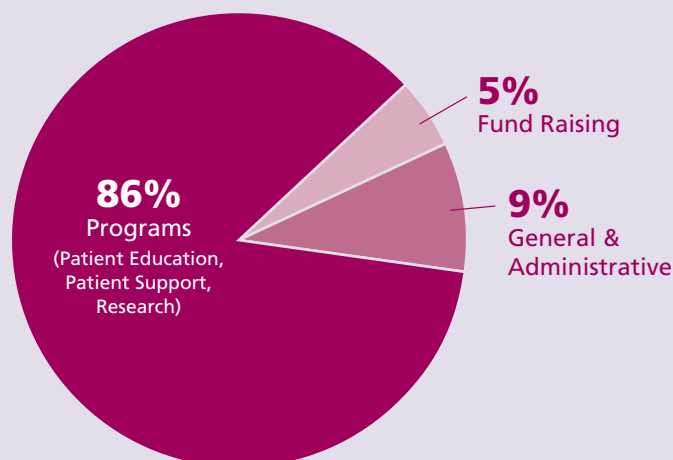
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Income Funding



Contributions	\$163,497
Corporate Sponsorships & Grants	\$819,840
Conference Fees	\$373,860
Membership Dues	\$141,262
Research Donations	\$74,698
Sales, Investment Income & Other Revenue	\$48,383
Total	\$1,621,540

How The Funds Were Used



\$0.86 of every \$1.00
goes directly to programs that support
and educate the ITP community.

Programs	\$909,921
General & Administrative	\$98,527
Fund Raising	\$55,864
Total	\$1,064,312

Net Assets at end of Year (accumulated) \$2,278,957

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Since 2017, our Research Program has led great advancements in the field by encouraging researchers to prioritize patient needs and by investing more than \$140,000 in seven research studies clearly focused on transforming the lives of ITP patients.



SUPPORT OUR 20/20 VISION

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Can we count on you to help? Together, we will help inspire and directly sustain the vital work of researchers seeking to unlock a cure for ITP.



Make a difference today at pdsa.org/20-20research



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