

# ANNUAL REPORT



EDUCATION. ADVOCACY. RESEARCH. SUPPORT.

## FROM THE PRESIDENT AND CEO

2020 was a year like no other. But amidst the fear, grief, isolation, and loss, we still achieved so much. I am pleased to present PDSA's 2020 Annual Report, where you will have an opportunity to share in our collective successes, learning more about how PDSA rose to the challenges of COVID-19.

As the pandemic quickly advanced around the globe, we at PDSA mobilized to respond to the evolving situation and to further support, educate, and meet the growing needs of the ITP community. We gained invaluable experience in remaining nimble and flexible as we put our expertise, resources, and passion to work in new and innovative ways to improve the ITP patient condition.



The PDSA leadership, Medical Advisors, and staff worked tirelessly to make available the most current information on COVID-19 and ITP – through dedicated webinars, our monthly e-News and quarterly *Platelet News*, and on our website and social media platforms. We also adapted our local support group meetings and *Pump It Up For Platelets!* events to virtual settings to ensure the ITP community stayed safe and connected.

Thanks to our generous donors, we were able to establish a number of rapidly deployed educational and research efforts to address COVID-19 and the health impact that it was having on ITP patients. We also attracted attention nationally and even internationally, providing data, commentary and expert opinions to numerous media outlets and prestigious scientific and medical journals.

The challenges of this year have laid bare how essential our work is – and how critical your support is to our mission. It is my honor to recognize your resilience, your commitment and engagement, and your unwavering support of PDSA and the greater ITP community. After all that we have been through, it is clear **we are stronger together**. I extend my heartfelt thanks to our members and donors for partnering with us. We could not do this without you.

Sincerely,

A handwritten signature in black ink, reading 'Caroline Kruse'.

Caroline Kruse  
President and CEO

### 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.

## PDSA BY THE NUMBERS

# 22 Years

of serving and giving voice to the ITP patient community



# 3 Websites



**200+**  
pages of  
content for  
ITP patients

**78,000+**  
total visitors  
to our websites  
each month

# 1,711

**Members and Donors**

whose charitable giving helped PDSA fulfill its mission and respond to the COVID-19 health crisis



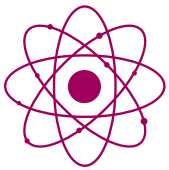
# 50

**\$1,000+ Circle of Hope Donors**

providing leadership support to all of PDSA's efforts



# 2 \$20,000 Research Grants



were awarded to fund original patient-centered ITP research, increasing our research funding impact to a total of **9 grants** and **\$180,000**

# 58

**Patient Support Groups**

Sustained by ITP patients, PDSA's support groups expanded to **29 states, 2 Canadian provinces** and **New Zealand**



# 1,139

**patients**

enrolled in PDSA's **ITP Natural History Study Registry**

# 14

**Medical Advisors**

Internationally renowned clinicians and researchers, all specialists in ITP



# 131

**Children with ITP participated in the Poke-R Club,**

designed to ease the fear of injections or "needle phobia" resulting from frequent blood draws and treatments



**PDSA's 20th Anniversary ITP Patient Conference**

made history. Hosted in a virtual format, we welcomed record attendance of

**670+ participants** from **25 countries**

# 700+ participants

from **44 countries**

across the globe tuned in for our **"Facts over Fear: COVID-19 & ITP" virtual town hall** in April 2020

# 19

**Pump It Up for Platelets! events were held**

attracting **189 participants** and **519 donors**, raising nearly **\$55,000** for PDSA programs and research



*"pump it up for Platelets!"*

NATIONAL WALK/RUN

**PDSA**

# 10

**Informational booklets on ITP**

for adults, teens, children, and women translated into **8 languages**



PDSA spearheads the **International ITP Alliance** with

**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

PDSA launched its **Healthcare Practitioner (HCP)** initiative to offer support and resources to **1500+** clinicians. **200+** HCP toolkits were distributed and PDSA.org/hcp received **6,700+** page views.



**1,000+ new members**





of PDSA's closed Facebook Group, bringing participant total to more than **15,000 members**



When it comes to ITP research, PDSA has 20/20 vision — a clear commitment to engaging 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.

We purposefully encourage and fund patient-centered studies to keep the ITP patient perspective at the center of the research process and to ensure outcomes that will directly impact patient quality of life.

Charitable support of PDSA's 20/20 ITP Research Campaign strengthens our efforts and helps sustain the momentum we have created in our many and varied research initiatives:

-  Since 2017, PDSA has awarded more than \$180,000 toward nine original ITP research studies.
-  In addition to encouraging and underwriting research, PDSA takes very seriously its role to also help inform research. In partnership with the National Organization for Rare Disorders (NORD), we continue to administer the one and only ITP Natural History Study Patient Registry, an important global collection of patient data which aims to inform ITP research and treatment development.
-  PDSA is also committed to the sharing of valuable data, writing scientific abstracts and developing posters to help inform physicians and industry partners on ITP and the patient experience. In 2020, PDSA staff authored 15 scientific publications, including the manuscript "Immune thrombocytopenia: the patient's perspective," which was published in the *Annals of Blood* (AOB) journal for high-quality research in hematology.
-  PDSA regularly hosts the Friday Morning ITP breakfast at the American Society of Hematology (ASH) Annual Meeting and Exposition, where global ITP investigators present their leading-edge ITP research. We also convene with the European Hematology Association (EHA) to share relevant research studies and initiatives, and partner with the Pediatric ITP Consortium of North America (ICON), a collaborative research effort of 49 pediatric hematology centers committed to advancing the care of children with immune thrombocytopenia (ITP).

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

The PDSA Research Program awards up to three \$20,000 research grants 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 Research Program is provided through gifts made to the 20/20 ITP Research Campaign.

### 2020 RESEARCH AWARDS



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, Madrid, Spain



Project Title:

***Real world effectiveness of second-line therapies for primary immune thrombocytopenia (ITP): a retrospective analysis of healthcare claims data***

Investigator: Karen Rascati, MD

Institution: University of Texas at Austin, USA



## INNOVATIVE ITP RESEARCH from the 2020 American Society of Hematology (ASH) Annual Meeting

Held virtually in 2020, the prestigious American Society of Hematology (ASH) Annual meeting attracted thousands of clinicians, scientists, pharmaceutical company personnel, and investment analysts worldwide to share groundbreaking research in the field of hematology. PDSA was well represented at the meeting and, as usual, hosted the coveted annual ITP Breakfast Meeting, attended by more than 200 people, in which Medical Advisors James Bussell, MD; Nichola Cooper, MD; Michele Lambert, MD; and John Semple, PhD, and 12 additional hematology experts from around the world presented their leading-edge ITP research.



## ITP Natural History Study Patient Registry

In partnership with the National Organization for Rare Disorders (NORD), PDSA continued to administer the one and only ITP Natural History Study Patient Registry in 2020, an important global collection of patient data which aims to inform ITP research and treatment development.



***"This group has been invaluable in providing support and reliable information for this complex unpredictable disease."***

– Darlene

***"Most hematologists are not familiar with PDSA, I wish every hematology office was somehow made aware of this resource."***

– Linda

## European Hematology Association (EHA) Congress Focused on the ITP Patient Perspective

In light of the COVID-19 global pandemic, the 25th Congress of the European Hematology Association (EHA) scheduled to take place in Frankfurt, Germany switched its annual meeting to a virtual format in June 2020. PDSA staff and members of the PDSA Medical Advisory Board participated in this important meeting by submitting multiple abstracts that were accepted in e-poster format.



## FACTS OVER FEAR: COVID-19 & ITP Virtual Town Hall

In April 2020, as the world was reeling from the onset of the COVID-19 pandemic, PDSA sprang into action to explore and share available information surrounding the impact of the virus on ITP patients. 700+ people from 44 countries across the globe tuned in for PDSA's virtual town hall with international renowned experts discussing COVID-19 and facts relevant to those living with immune thrombocytopenia (ITP). The event was live streamed and moderated by PDSA President and CEO Caroline Kruse and PDSA Medical Advisor James Bussel, MD, a leading hematologist and professor at Weill Cornell in New York. This event was the first of many hosted by PDSA to serve the ITP community on the very fluid and developing situation.



## Fifth Annual Global ITP Awareness Week and Meeting of the Minds

It's hard to believe that it's only been four years since ITP advocacy groups from around the world held their first in-person meeting and joined forces to create a global voice for immune thrombocytopenia



patients as the International ITP Alliance. COVID-19 cannot stop the advocacy efforts of these global partners. On Friday, October 9th, 17 delegates from 12 countries Zoomed their way to awareness as part of the ITP Support Association's UK ITP Convention!

## The Patient Voice

Melissa Hilsabeck, member of the PDSA Board of Directors; PDSA ITP conference ambassador; Orange County, CA support group facilitator; and Pump It Up For Platelets walk/run organizer shared her ITP journey during Dova Pharmaceuticals National Sales Meeting in San Diego, CA, in February 2020.



***"Thank you for being an advocate for persons with ITP."***

— Kelly G.

***"The PDSA is an incredible organization! They have the top ITP specialists and connect people all across the world."***

— Gen K.



## PDSA Canada

PDSA Research Program Manager Jennifer DiRaimo attended the Canadian Organization for Rare Disorders (CORD) conference in March 2020 and joined CORD's President and CEO Durhane Wong-Rieger in their organized rally to help voice the concerns of the rare disease community on Parliament Hill, in Ottawa Ontario, Canada.

## PDSA Presentations:

- PDSA President and CEO Caroline Kruse spoke at the Amgen National Sales Meeting in Dallas, Texas, along with two ITP patients, in February 2020.
- PDSA Board Member Melissa Hilsabeck presented at the Dova Pharmaceuticals National Sales Meeting in San Diego, CA, in February 2020.
- PDSA's "Facts Over Fear: COVID-19 & ITP" Virtual Town Hall, presented in April 2020, was moderated by both PDSA President and CEO Caroline Kruse and PDSA Medical Advisor, Hematologist, and Professor at Weill Cornell James Bussell, MD.
- PDSA President and CEO Caroline Kruse, Research Coordinator Alexandra Kruse, Research Program Manager Jennifer DiRaimo, and PDSA Medical Advisor Michele Lambert, MD, presented their e-poster abstract "Mental Health And Physical Function In Pediatric Immune Thrombocytopenia (ITP): Quality Of Life Data From The Platelet Disorder Support Association (PDSA) Patient Registry" at the European Hematology Association (EHA) virtual annual meeting in June 2020.
- PDSA President and CEO Caroline Kruse, Research Coordinator Alexandra Kruse, and PDSA Medical Advisors James Bussell, MD, Nichola Cooper, MD and Drew Provan, MD were authors on the following e-poster abstracts presented at the European Hematology Association (EHA) virtual annual meeting in June 2020: "Higher Symptom Burden In Patients With Immune Thrombocytopenia Experiencing Fatigue: Results From The ITP World Impact Survey (I-WISH)," "A Patient's Perspective On Impact Of Immune Thrombocytopenia On Emotional Wellbeing: ITP World Impact Survey (I-WISH)," and "Patient's Reported Perceptions On Satisfaction With Immune Thrombocytopenia Treatments: Results From The ITP World Impact Survey (I-WISH)."
- PDSA Medical Advisors James Bussell, MD, Craig Kessler, MD, Michele Lambert, MD, John Semple, PhD, and Michael Tarantino, MD, presented PDSA's pre-Summit Workshop "ITP Journal Club" focusing on cutting-edge clinical and laboratory research at the Thrombosis and Hemostasis Societies of North America (THSNA) Virtual Summit in October 2020.
- The following research studies, authored by PDSA staff and advisors, or funded by PDSA, were presented at the 62nd American Society of Hematology (ASH) Virtual Annual Meeting in December 2020: "Anxiety In Adult Patients Living With ITP Stratified Across Different Treatment Types and Groups: A Survey Study by PDSA," "Tapering Thrombopoietin Receptor Agonists In Primary Immune Thrombocytopenia: Recommendations Based On The RAND/UCLA Modified Delphi Panel Method," "Decision Aid to Support Shared Decision Making in Pediatric Refractory Immune Thrombocytopenia," and "Importance Of Glycoside Residues On Haemostasis of Patients With Immune Thrombocytopenia."



## PDSA Participated in the Following Meetings:

- American Society of Hematology (ASH) 62nd Virtual Annual Meeting and Exposition
- Immunoglobulin National Society (IgNS) National Conference
- National Organization for Rare Disorders (NORD) 2020 Rare Diseases & Orphan Products Breakthrough Summit
- Thrombosis & Hemostasis Summit of North America (THSNA)
- Foundation for Women & Girls with Blood Disorders (FWGBD) 2020 Conference
- 25th Congress of the European Hematology Association (EHA)
- UK and Ireland ITP Support Association Convention

## 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**

***"My daughter has only been diagnosed 4 months, but it's already been a rollercoaster, and she said it was nice to see that she's not alone, that other people are going through the same thing. So thank you again and again for doing this."***

– Elly

# Virtual ITP Conference 2020 Makes History!

Nothing can fully match the benefit of attending PDSA's ITP Conference in person. In fact, attendees often describe it as a life-changing experience. When the pandemic prohibited our coming together in person and threatened the hosting of our 2020 conference altogether, we at PDSA weren't ready to throw in the towel. Instead, we were more determined than ever to connect the ITP community, our Medical Advisors, and industry partners for this very important meeting.

With "necessity as the mother of invention," we focused our efforts on developing an online conference platform which would allow the ITP community to come together, despite the pandemic. And so, in just two months' time, PDSA's virtual ITP "Alone Together" conference was launched. Breaking barriers and connecting the global ITP community during a time of great uncertainty, our 20th Anniversary conference was the largest in PDSA's history, attracting **670+ registrants from 25 countries and 45 states.**



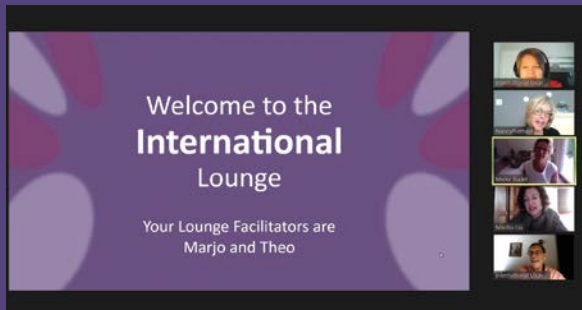
The 2020 ITP Conference virtual Ballroom.



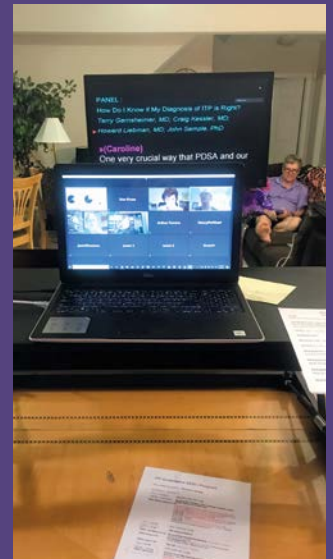
Where real life connects with science – the virtual Exhibit Hall.



An ITP community favorite – PDSA Medical Advisor Michael Tarantino, MD presents Communicating with Your Doctor.



The global ITP community connected during the conference through the virtual International Lounge.



The view from President and CEO Caroline Kruse's perch where she moderated the conference with the help of her trusty technical assistant (husband Ken) in the background.

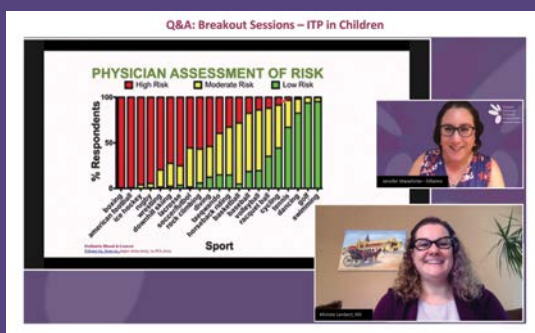
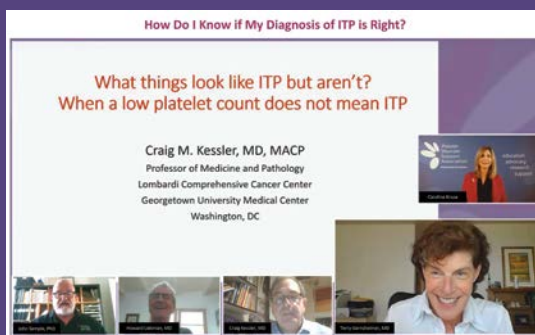
# ITP CONFERENCE 2020



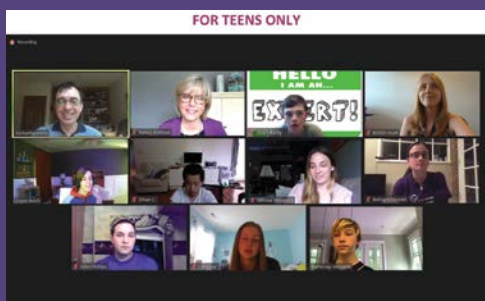
*Behind the Scenes: PDSA Website and Social Media Manager Jeff Cooper led the conference production with a crew of six from Phoenix, AZ.*



*Participants enjoyed the 2020 Virtual ITP Conference from their homes, offices, and even the great outdoors!*



*Two of the popular ITP sessions presented by PDSA Medical Advisors and moderated by PDSA staff.*



*PDSA Medical Advisor Dr. Michael Tarantino gathered his expert panel of adolescent patients to better understand the patient perspective.*

***"Wonderful conference! Hope the virtual access can remain a part for the future. The lounge opportunities were great! Thanks so much – again."***  
– Dail

***"This was my first virtual conference, and it has been a great weekend. A wonderful and successful event. Thank you all staff and speakers. Best wishes from the Netherlands."***  
– Brigitte D.

***"I just wanted to thank you for putting on such a wonderful, thoughtful and informative conference this year. I had many questions answered, was able to connect with some new patients, and most importantly, was reminded that I am not in this alone..."i>***  
– Cory B.

***"Great job this weekend! Loved the familiar format and especially if you have attended conferences in the past. The medical professionals always on their game and love how well they work together. Always feel they are working for the members. Lots of great information supplied and always come away with so much knowledge that someone should warn my doctor. We are going to need a longer appointment next visit."***  
– Denis S.

## AWARENESS & OUTREACH

### Social Networking

 **29,214+**

Facebook Likes & Followers

 **15,900+**

Facebook Group Members

 **1,618+**

Instagram Followers @PDSA\_ITP

 **1,533+**

Twitter Followers @PDSA\_ITP

 **119,290+**

YouTube Video Views PDSAorg

 **10,502+**

PDSA.org Discussion Group Members

*"My 17-year-old daughter Hannah has recently been diagnosed with ITP (unclear whether it's primary or secondary) at Sick Kids Hospital here in Toronto and while this has been an extremely stressful and difficult period for us, I have found your organization (now, as a new member) and associated website to be superbly helpful and encouraging. We are just beginning to come to terms with this illness and what it means to our child, so thank you for being there for us and for families all across Canada and the US who are suffering from this disease."*

— Mark

*"Thank you. I've set my Facebook feed so your posts appear first – our family values your efforts very much."*

— Les T.



**pdsa.org**

**45,000**

Unique Visits  
per Month

**73,518+**

Total Visits per Month



**ITPwalk.org**

**1,000**

Unique Visits  
per Month

**1,461+**

Total Visits per Month



**GlobalITP.org**

**2,052**

Unique Visits  
per Month

**3,185+**

Total Visits per Month



# September = ITP Awareness Month + Sport Purple for Platelets Day!

September 2020 was a great ITP awareness milestone – the 10-year anniversary of PDSA's successful designation of National ITP Awareness Month! Every September for the past decade the ITP community is highlighted and honored as we work together to shine additional light on this rare bleeding disorder and observe the ongoing courage of ITP warriors around the world. This special month of awareness events and activities includes a wildly popular culminating event, Sport Purple for Platelets Day – and the ITP community is more than happy to step up and show its colors! 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.



**"Amazing PDSA!!  
... Just when I  
think you can't  
possibly get any  
more awesome,  
there you all  
are wowing me  
again!"**

– Beth

# PDSA's Proactive Pandemic

2020 will be long remembered as the year the coronavirus pandemic sent shockwaves around the world and, for the first time, the general public experienced what ITP patients live with every day – fear of the unknown. As the pandemic advanced around the globe, PDSA mobilized quickly to respond to the evolving COVID-19 health crisis to further support, educate, and meet the growing needs of the ITP community. In addition to hosting frequent online events on COVID-19 & ITP, we also developed a “go to” COVID-19 & ITP Resource Hub to provide accurate, current, and reliable information and expanded support services. Learn more about our proactive COVID-19 response below.

### COVID-19 & ITP VIDEOS & WEBINARS

As questions and concerns surrounding the direct effects of coronavirus on the ITP community escalated, PDSA organized a virtual town hall-style meeting where ITP specialists and other experts presented emerging data, facts and answered COVID-19 and ITP related questions.

***Facts over Fear: COVID-19 & ITP Virtual Town Hall Meeting with Global ITP Experts – Part 1 (April 3, 2020), moderated by PDSA President and CEO Caroline Kruse and PDSA Medical Advisor James Bussel, MD***

Experts included Steven M. Holland, MD of the National Institutes of Health; Immunologist Charlotte Cunningham-Rundles, MD, PhD, Mount Sinai Hospital in New York City, Professor Francesco Rodeghiero, MD, PhD, Vincenza Italy; Runhui Wu, MD, PhD, Beijing, China; and PDSA Medical Advisors Nichola Cooper, MD, and David Kuter, MD.

- 2,615 video views on pdsa.org
- 700 registrants from 43 countries
- 719 video views on globalITP.org
- Video content translated into Italian and Hebrew



***Facts over Fear: COVID-19 & ITP Virtual Town Hall Meeting with Global ITP Experts – Part 2 (July 30, 2020), moderated by PDSA President and CEO Caroline Kruse and PDSA Medical Advisor James Bussel, MD***

Experts included Steven M. Holland, MD of the National Institutes of Health; Immunologist Charlotte Cunningham-Rundles, MD, PhD, Mount Sinai Hospital in New York City; Kristen Marks, MD, Weill Cornell Medicine, Bruce Sachais, MD, PhD, New York Blood Center; and PDSA medical



advisors Nichola Cooper, MD, and Howard Liebman, MD.

- 391 video views on pdsa.org
- 600 registrants from 19 countries

***“I wanted to thank you both and also the other Drs on the call for a wonderful webinar last Monday evening. I wrote so fast that I actually had hand cramps - so much information! I learned so much and am so grateful to the PDSA for sponsoring such an event! ... I’m also very grateful that the PDSA is doing a survey so we can also see how all the ITP patients are doing with the vaccine”***

– Marcia

***“Thank you so much for putting on this webinar [for] COVID-19 vaccines for ITP patients. I found all the information was excellent.”***

– Ron

# Response

## PDSA'S COVID-19 & ITP RESOURCES

### EXPERT GUIDELINES & STATEMENTS

Provided essential protocols and expert guidance including current recommendations of the Medical Advisory Board of PDSA, American Society of Hematology (ASH) on COVID-19 & ITP, important information for splenectomized patients, and the second most downloaded (1,134 times) document on pdsa.org – *COVID-19 and ITP in Pediatric ITP: What You Need to Know*.

### COVID-19 & ITP IN THE NEWS

Supplied patients and caregivers with a reliable directory of reports concerning COVID-19 and the ITP community.

### EXPERT Q & A VIDEO CLIPS

Individual video series of abbreviated excerpts from expert insights into COVID-19 and ITP.

- 1,866 page views

### GENERAL COVID-19 RESOURCES

Supplied general patient-friendly COVID resources including mental health/stress/anxiety management, essential resources from the CDC and FDA, and multi-lingual materials.

### PDSA CLOSED FACEBOOK GROUP

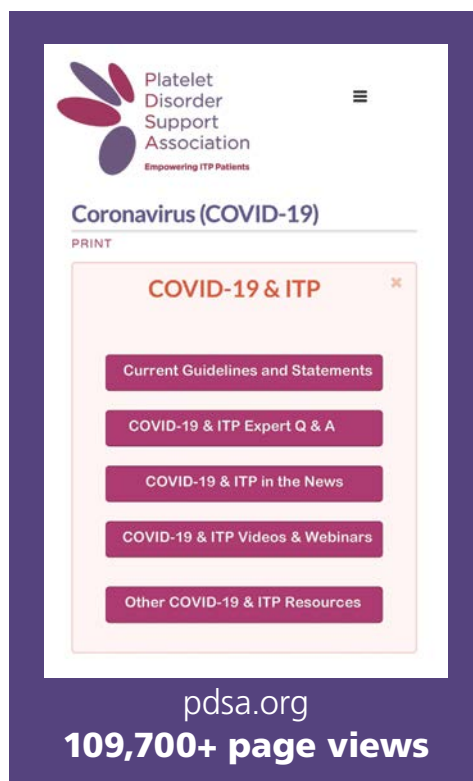
1,000+ new members of PDSA's closed Facebook Group, bringing participant total to more than 15,000 members.

### VIRTUAL ITP CONFERENCE 2020

Our 20th Anniversary conference was the largest in PDSA's history, attracting 670+ registrants from 25 countries and 45 states. See a full summary of this first-ever virtual ITP Conference on pages 8 and 9.

### PDSA SUPPORT GROUP PROGRAM

58 patient support groups actively participated in virtual meetings throughout 2020. Learn more about their success on Page 14.



***"Dear PDSA! Despite COVID-19, you did it again, you hit it right out of the park! Great job!"***

– Marcia F.

***"Thank you for coordinating the excellent webinar on Covid and ITP tonight. It was so relevant! I am waiting for an appointment but had some uncertainty which was eliminated by the emphatic encouragement given."***

– Katharine

# Support Groups – You are Not Alone!

In 2020, the need for community became more important than ever. When COVID-19 shut down countries around the world, PDSA and our amazing ITP community worked together to ensure that ITP patients everywhere felt safe, informed, and connected.

Our dedicated network of support group facilitators instantly stepped forward and welcomed the opportunity to hold their meetings via video or teleconference – and medical experts from PDSA's Medical Advisory Board and the Pediatric ITP Consortium of North America (ICON) offered to join the virtual meetings to answer questions. This virtual approach provided a much-needed lifeline for patients and caregivers alike and offered them the chance to engage with one another and to benefit from PDSA's comprehensive collection of timely information, exceptional resources, and heartening support.

In addition to regional online support group events, PDSA also hosted two very successful live ITP Kids & Parents Video Conferences. On April 21, children with ITP and their parents in the Eastern and Central time zones had the opportunity to converse with one another and with pediatric ITP specialist Jenny Despotovic, MD of Texas Children's Hospital. On April 28, children and families in the Pacific and Mountain time zones participated in a second ITP Kids & Parents video conference during which they heard from and spoke with Kristin Shimano, MD, another pediatric ITP specialist from the University of California, San Francisco (UCSF). Each meeting dedicated 30 minutes for the kids to chat with one another, followed by a 45-minute Q & A segment with the medical experts, and closed with an informative parent discussion. For many of the children attending, this was their first time even "seeing" another child with ITP!



*"It was really nice seeing a few familiar faces and meeting everyone else! It's really nice to have this community... thanks so much to PDSA."*

– Giselle

*"As a parent of an ITP patient, it is reassuring to know there are others out there... I am really grateful to all of you sharing your stories."*

– Kristin

*"Thank you very much for hosting tonight's meeting!! [We] found it informative and helpful. [My daughter] felt a certain sense of relief knowing that she is not the only teenager living through this and it was nice for me to see that many parents have the same questions as I. We very much appreciate Dr. Grace taking time from her busy schedule to answer questions!"*

– Erin

*"I have lived with ITP for sixteen years! ... It has been a bumpy ride but my faith and this support group has been a guiding light! Thanks for being here for us!"*

– Debra M.

## EDUCATION & SUPPORT



### In 2020:

9

new support groups launched

58

active support groups in 29 of the United States, 2 Canadian provinces, and New Zealand

40

meetings held with a total of 498 participants

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!



To help kids facing the trials associated with managing their ITP and the extreme fear of injections or needles – or “needle phobia” – that often results from treatments, we offer the ITP POKE-R CLUB<sup>SM</sup>, an exclusive free clinical support program for PDSA members in the United States and Canada.



In addition to providing our young Poke-R Club members with special tokens and prizes when they've reached certain numbers of needle “pokes,” we also provide them with a Buzzy®, a drug-free, palm-sized pain relief device which combines cold and vibration to help eliminate or inhibit needle pain by placing stimuli “between the brain and the pain.”

PDSA's ITP Poke-R Club welcomed **24 new members** in 2020.

**131 children**, ages 2 to 17, are currently enrolled in this special program, representing **34 states, 4 provinces** and **2 countries!**

*“What a great idea for little kiddos! [My daughter] often feels like she is being punished and is very confused as to why she misses play school, or outings with family and friends to be at the Drs or hospital. I think this little ‘rewards’ club would make her feel better and give her something to look forward to after so many lab visits.”*

– Allison R., mom of Dayva



### PDSA PUBLICATIONS

PDSA publishes informational booklets, articles, *The Platelet News* quarterly magazine, and monthly e-News.

2020 brought an update to our *ITP in Children* booklet, featuring the latest information and frequently asked questions to help parents navigate their child's diagnosis and treatment. *ITP in Children* and *When a Child Has ITP*, featuring the psychosocial aspects of ITP, are now available in Arabic, Chinese, English, French, Finnish, Hungarian and Spanish.



### 2020 PDSA College Scholarship Winners!

#### \$1,500 RECIPIENT



**Gretchen Mason, Carrboro, NC**  
University of North Carolina at Chapel Hill

"My diagnosis of ITP has drastically changed my own perspective on what matters most and has fueled a passion of equitable health reform."

#### \$750 RECIPIENT

**Julian Cohen, El Paso, TX**  
Texas Tech University



"As a recipient of the PDSA College Scholarship, I am extremely grateful for the support of the Platelet Disorder Support Association to further my education. This generous gift will allow me to begin the pursuit of my dreams to become a healthcare provider and in turn, help others heal. Thank you very much for the wonderful recognition and assistance."

#### \$250 BOOK AWARD RECIPIENTS



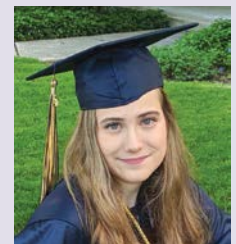
**Savannah Ingle**  
Mooresville, NC  
University of North Carolina at Chapel Hill

"My ITP has taught me that I am a survivor and although my situation may seem bleak, there is always a way to persevere and power through to the end."



**Rachel Netz**  
Portage, MI  
Hope College

"MY ITP has undoubtedly shaped me into the person I am today, and I am grateful for the family members, friends, medical professionals, and ITP experts who have helped me to navigate my journey of self-growth."



**Elizabeth Snyder**  
Arlington Heights, IL  
Indiana Wesleyan University

"My experiences with ITP have prepared me to encourage others going through similar circumstances. Just as ITP altered my outlook on life, I aspire to cause positive change in the lives of my patients."



***"The PDSA resources – paper, online, annual meetings – and more personal support for families are exceptional! Always glad to see when patients/families take advantage of these opportunities. And also importantly, is the drive for research and support of the trainees and medical personnel to accomplish this."***

– Melissa R.

## Connecting Science With Everyday Life

For over 20 years, PDSA has proudly served as a trusted resource for the scientific community – connecting ITP patients and caregivers with patient-friendly educational materials, programs, and support.

In 2020, we launched the Healthcare Practitioner (HCP) Outreach Program to further support clinicians and connect the community with the latest ITP protocols, cutting edge research and innovative therapies being developed worldwide.

### Treatment Guidelines and Consensus Statements

Our comprehensive directory of clinical guidelines and consensus statements provide easy access for clinicians to stay current in today's rapidly changing healthcare landscape.

- International Consensus Report on ITP (updated 2019) – #1 downloaded document on [pdsa.org](https://pdsa.org) (1,354 downloads in 2020)

### Expert Opinions in ITP Management

In this extensive video library organized by topic, ITP experts explore disease course and treatments in immune thrombocytopenia.

### Research Resources

Research is the key to learning more about what causes ITP and determines effective treatments. This hyperlinked directory of resources offers researchers and clinicians easy access to ongoing studies and clinical trials.

### PDSA Research: posters, publications, and awards

This online library archives PDSA's rapidly expanding list of published research works. With hyperlinked titles, the directory disseminates insights focused on improving ITP patients' quality of life.

### Patient Education Resources

This directory (with online hyperlinks) of resources was developed to help clinicians communicate the intricacies of ITP to patients and caregivers.

### HCP Toolkit

Available online and in print, PDSA connects clinicians with professional resources and equips them with PDSA's extensive library of patient-friendly materials and directory of support services.

- [PDSA.org/hcp](https://pdsa.org/hcp) – 6,700+ page views (July – December 2020)
- 200+ Toolkits distributed via direct mail (October – December 2020)

### ITP Patient Assessment Questionnaire (ITP-PAQ)

This 44-item questionnaire is a validated disease-specific measurement tool that assesses health-related quality of life (HRQoL) in adult subjects with ITP.

# Virtual Pump It Up For Platelets! 2020

Despite COVID-19, ITP Awareness Champions across the United States and Canada walked their way to ITP Awareness!



**TOTAL RAISED:**  
**\$54,919**

**TOTAL PARTICIPANTS:**  
**189**

**# OF TEAMS:**  
**19**

**# OF DONORS:**  
**519**



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**\$15,700**

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Tracey Parker organized "Parker's Platelet Posse" for a 2020 Virtual Pump It Up For Platelets! event in Michigan.



The Randolph Family formed "Team Cade" for their Poses for Platelets yoga event in Ohio.

***"I really appreciate how much you care about all of us involved with the PDSA! It's such a wonderful organization and I am so thankful for being a member!"***

— Marcia

***"Let me also take this opportunity to express my thanks to your organization for all of the work it does on behalf of ITP patients. I cannot begin to tell you how helpful all of the information on your website and the information you sent me by mail has been."***

— Wes

## 2020 CONTRIBUTIONS AND FINANCES

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 2020.

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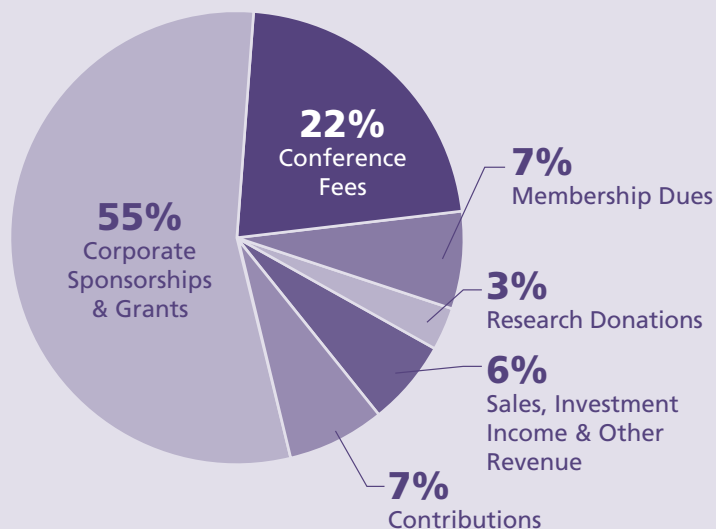
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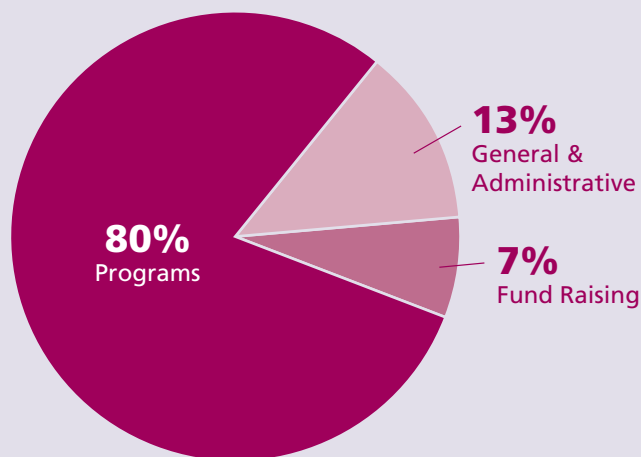
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### Income Funding



Contributions	\$150,681
Corporate Sponsorships & Grants	\$1,110,488
Conference Fees	\$446,845
Membership Dues	\$136,519
Research Donations	\$56,632
Sales, Investment Income & Other Revenue	\$128,218
<b>Total</b>	<b>\$2,029,383</b>

### How The Funds Were Used



Programs	\$712,223
General & Administrative	\$114,221
Fund Raising	\$59,561
<b>Total</b>	<b>\$886,005</b>
<b>Net Assets at end of Year (accumulated)</b>	<b>\$3,422,336</b>

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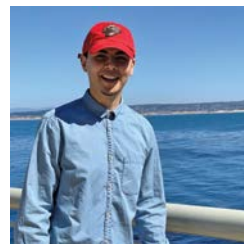
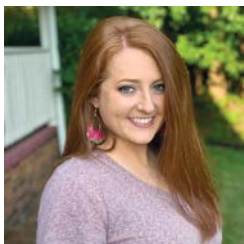
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# PDSA 20/20 ITP Research Campaign: *Changing the Lives* of ITP Patients

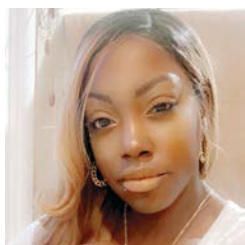
When it comes to the ITP community, **PDSA has 20/20 vision** – a clear commitment to improving ITP patient health outcomes and quality of life through patient-centered research.



## **RESEARCH can change the lives of ITP patients. And, working together, so can we.**

Our efforts are strengthened and more successful with **YOU** on our side. The charitable support of the ITP community has allowed us to:

- ✓ Prioritize patient needs and lead advancements in ITP research,
- ✓ Invest \$180,000+ in funding toward nine (9) original ITP research studies,
- ✓ Author countless scientific articles and publications on the ITP condition, and
- ✓ Administer the one and only ITP Natural History Study Patient Registry, an invaluable global collection of patient data which serves to inform ITP research and treatment development - and now includes the COVID-19 & ITP Research Survey.



## **SUPPORT OUR 20/20 VISION**

**Donations to the 20/20 ITP Research Campaign directly support PDSA's Research Program.**

Your generosity will reinforce our collective influence on ITP patient-centered research and will bring about new answers, findings, and remedies for the ITP community.

***Make a difference today at [pdsa.org/20-20research](https://pdsa.org/20-20research)***



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