



2016

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.



From the Executive Director

Dear Friends of PDSA,

I am proud to present the Platelet Disorder Support Association's 2016 Annual Report. Let me take a moment to thank you for your part in helping to make this a successful year for PDSA and the ITP patient community. In these pages we recognize all those who support PDSA and make possible the important work we do. These range from our educational and support services through the PDSA website, discussion group and social media outlets, to our numerous publications, local support groups and annual conference, to our patient referral line.

In 2016, PDSA was the recipient of two prominent awards that could enhance our understanding of ITP, improve patient quality of life, and lead to the development of better treatments and possibly a cure one day.

We are thrilled to be the recipient of the Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute, which provides essential funding to assist PDSA in the development of our Framework and Priorities Guidelines for supporting ITP research projects. To further our efforts surrounding research, we established a Patient Advisory Committee to ensure that the ITP patient perspective and voice are at the center of our research priorities.

Equally impactful is PDSA's selection by the National Organization for Rare Disorders (NORD) to participate in the NORD Natural History Study Registry Project, a cooperative agreement with the U.S. Food and Drug Administration (FDA). Designed to capture data on the natural progression of ITP, this transformative patient registry project will enable PDSA to collect data on diagnosis and treatment, management of care, quality of life, and clinician reporting.

Another exciting initiative spearheaded by PDSA in 2016 was the founding of the International ITP Alliance, an intercontinental partnership of ITP patient support organizations committed to education, awareness and establishing a global voice for ITP patients. Through the creation of the website www.globalitp.org and Global ITP Awareness Week, we made great strides in raising awareness for ITP around the world.

We remain heartened by messages from our members indicating that our information and support have made a difference in their journey toward better health. This work can only advance meaningfully if it is supported by patients, caregivers, our industry partners, and the medical community. We at PDSA thank you for the important role you have played in our success. I hope you take pride in knowing that your personal efforts and contribution have made a difference and have helped to ease the burden of those living with this disease.

A handwritten signature in black ink that reads "Caroline Kruse".

Caroline Kruse
Executive Director

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

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.

What is ITP?

ITP, immune thrombocytopenia (also known as immune or idiopathic thrombocytopenic purpura) is an autoimmune disease. In autoimmune diseases, the body mounts an immune attack toward one or more seemingly normal organ systems. In ITP, platelets are the target. They are marked as foreign by the immune system and eliminated in the spleen, the liver, and by other means. In addition to increased platelet destruction, some people with ITP also have impaired platelet production.

A normal platelet count is between 150,000 and 400,000/microliter of blood. If someone has a platelet count lower than 100,000/microliter of blood with no other reason for low platelets, that person is considered to have ITP. There is no accurate, definitive test to diagnose ITP.

With few platelets, people with ITP often have bleeding symptoms such as spontaneous bruising, petechiae (pe-TEEK-ee-ay), tiny red dots on the skin, or for women, heavy menses. More severe bleeding symptoms include blood blisters on the inside of the mouth, blood in the urine or stool, or bleeding in the brain.

It was once thought that ITP was a simple disease... antibody coated platelets are removed by the spleen, leaving a reduced platelet count. However, as researchers study each step, from platelet production to platelet elimination, they continue to find subtleties to this process that have made a difference in how the disease is viewed and treated. There are nuances to the diagnosis, differences in the disease between children and adults, and variations in how the disease responds to treatments.



Advocacy & Research Highlights

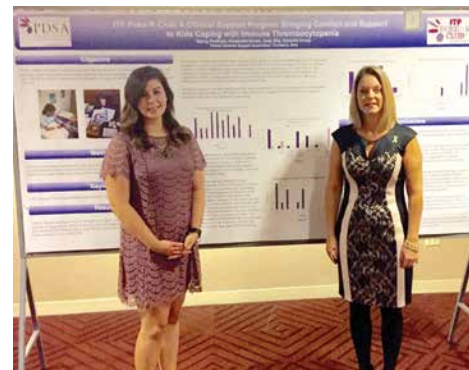
PDSA staff attended the following meetings:

- American Society of Hematology (ASH)
- 21st Congress of the European Hematology Association (EHA)
- National Summit on Autoimmune Disease
- NORD Rare Diseases & Orphan Products Breakthrough Summit
- 2nd PCORI (Patient-Centered Outcomes Research Institute) Annual Meeting
- Plasma Protein Therapeutics Association Stakeholders Meeting
- 9th Annual NIH Rare Disease Day
- 3rd Biennial Summit of the Thrombosis & Hemostasis Societies of North America (THSNA)



"I want to tell you that since I joined the group, I have had more tools to face my daughter's condition from a medical perspective, but especially from a resiliency (humane) perspective. In Mexico there are no groups like the one you facilitate, and I feel the support of other parents who are facing a similar condition, and it is a good network to gain perspective while our kids are sick."

—Yvette



NORD Rare Diseases & Orphan Products Breakthrough Summit

(L – R) PDSA's Research Coordinator Alexandra Kruse and Director of Marketing Nancy Potthast pose with their winning ITP Poke-R ClubSM poster at the October 17-18, 2016 NORD Rare Diseases and Orphan Products Breakthrough Summit in Arlington, VA



ITP Global Support Group Meeting

International delegates from 8 countries attended the ITP Global Support Group Meeting on Friday, September 16, 2016 at The Shaw Country House Hotel in the UK. Representatives from International ITP Alliance member organizations included Denmark, Finland, India, Italy, Netherlands, Sweden, United Kingdom, and PDSA Executive Director Caroline Kruse and Director of Marketing Nancy Potthast from the United States of America.



American Society of Hematology (ASH) Meeting

PDSA Board Chair Peter Pruitt and his wife Barbara greeted visitors to the PDSA booth during the 58th ASH meeting in San Diego, CA on Dec. 2-6, 2016

Awareness Reach & Social Media Growth

Social Networking



10,000+

Facebook Likes & Friends



Visit our Facebook page
and join our closed group!
/plateletdisorder



250+

Instagram Followers
@PDSA_ITP



900+

Twitter Followers
@PDSA_ITP



70,000+

YouTube Video Views
PDSAorg



7,600+

PDSA.org Discussion
Forum Members

"Thank you.

*I've set my facebook feed
so your posts appear first—
our family values your
efforts very much."*

— Les T.



5,000

US and International
Calls/Emails per Year

900

Participants in PDSA's
Name Exchange Program

*"I'm newly diagnosed
at age 74. This website
is a resource I will use
frequently. Thanks."*

— Yehuda C.



www.pdsa.org

200

Pages of Free
Information

50,000

Unique Visits
per Month

3 Million

Hits per Month



130

Countries
Represented

70,000

Total Visits per
Month

Informational Booklets and Numerous Articles

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



Quarterly Newsletters

Circle of Hope
and
The Platelet News



Monthly E-Newsletter

The Platelet News



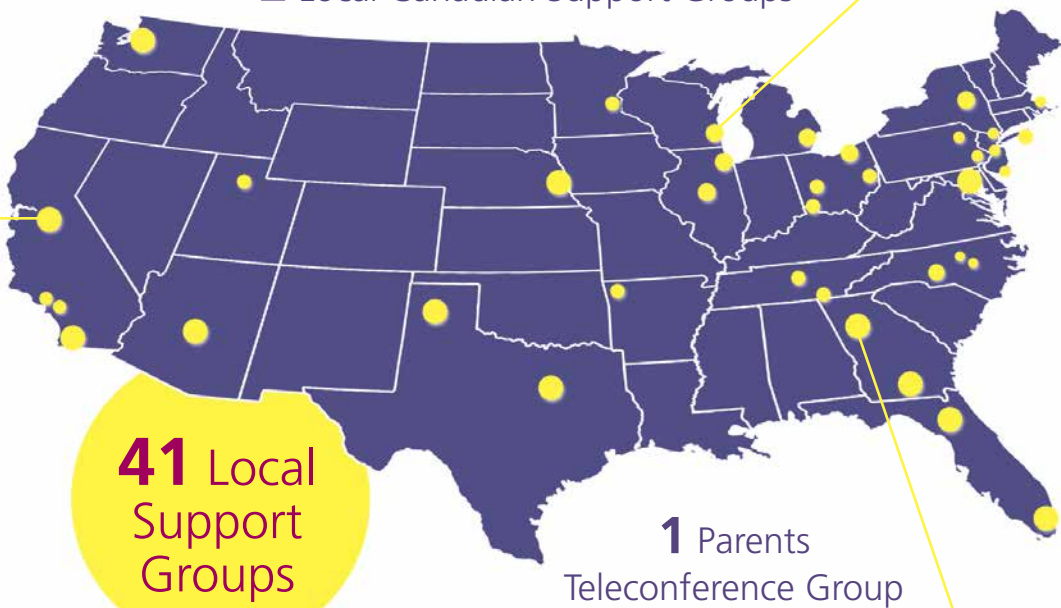
Education & Support Program Highlights



WI Support Group

Mother Nature was no match for these ITP Warriors. Despite a blinding April storm, the Wisconsin ITP Support Group co-facilitated by Kim Everett (far right) and Trudy Sensat (center rear with green scarf) filled the room with new attendees!

- 1 Canadian Teleconference Group
- 2 Local Canadian Support Groups



41 Local Support Groups

1 Parents Teleconference Group

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) in July. ITP Warrior and Sacramento group co-facilitator John Phillips is pictured (center, left) with Josh Phegley (center, right).



Atlanta Support Group

Members of the Atlanta, GA Support Group at the February 27th meeting





57

57 children in the program from ages **2-16**

57 kits distributed

57 prizes distributed for a total of **760** needle pokes



Maddie F. happily displays the award and prize she won in the Poke-R-ClubSM



Logan R. with a couple of his favorite Poke-R ClubSM prizes – a baseball and MLB trading card signed by Oakland A's catcher and ITP patient, Josh Phegley!

***"Caden loved his prize!
He is now a huge Oakland A's fan and has put their gear on his Christmas list!!! This has been a huge inspiration for him! Thank you! I hope you have a great holiday!!"***

– Jennifer S.

"Remembering the anniversary of his diagnosis and in gratitude for the year and a half of normal platelets he's had since treatment with Rituxan. We are thankful for all PDSA has done for him."

– Jana R.



Cayden K. proudly shows off his Buzzy®



2016 \$1,000 Scholarship Award Winner – John Phillips

Elk Grove, CA
Cosumnes River College

"My diagnosis of ITP was very shocking. It turned my life upside down. I had to learn about a disease I had never heard of before and change my lifestyle completely. I had to deal with terrible symptoms from medication. I could have just given up and taken the easy route, but I decided to use my experience to make a difference in the world. ...the best way I can help people is to become a hematologist... I could make the difference for and provide support for someone newly diagnosed better than a regular hematologist, because I have had personal experience with this."

Community Events & Outreach Highlights

ITP Conference 2016



290

Attendees (Largest Ever)

159

First Time Attendees

10

Speakers



7

Exhibitors

\$23,930

in Scholarship Dollars Awarded

45

Scholarships Awarded

9 Countries

US, Canada, Mexico, UK, Germany, Sweden, Austria, Argentina, Pakistan

Introduced New Patient Centered Outcomes Research (PCOR)

Separate Teen/Young Adult Track

"ITP Conference in Orlando was excellent! Heard a lot about the treatment that put me into remission. The best part is always the people. Got to meet some I've 'known' for several years through FB groups. Looking forward to next year in Arizona!"

– Mary I.



Doctors who discussed top concerns of ITP patients at this year's ITP conference



Dr. Terry Gernsheimer talks with an attendee at the ITP conference in Orlando



The teen session at ITP Conference 2016

"Worth all the effort to get to 2016 Orlando Conference! Two benefits are the interaction with others with ITP and the information."

– Jerry J.



The fall 2016 Sport Purple for Platelets Day, held September 30th, once again raised public awareness of ITP and platelets across the US and around the world. Adults, teens, and kids wore bracelets, tee shirts, and sported purple attire, fingernails, and hair. Schools, offices, and sports teams wore their purple shirts. Even pets wearing purple joined in the fun!





“pump it up for Platelets!”
NATIONAL WALK/RUN
PDSA
PLATELET DISORDER
SUPPORT ASSOCIATION



ORLANDO, FL



RANCHO CUCAMONGA, CA



ORANGE, CA



AMES, IA



CRANBERRY TWP, PA



CHICAGO, IL



SANDGAP, KY



CLEVELAND, OH



Cherie Zimmerman



John Lugo and boys

2016 Fundraisers/Walks

Pump It Up For Platelets! Chicago, IL

\$15,239.31

Emily Auterson (Team Organizer)
Susan Frank
(Event & Team Organizer)
Maria Soledad Ruiz
(Team Organizer)
Trish & Paul Santaromana
(Event & Team Organizer)
Jennifer & Aaron Slad
(Event & Team Organizer)

Pump It Up For Platelets! Orange Co., CA

\$7,536.00

Cathy & Raul Aldama
(Event & Team Organizer)
Leilani de Castro
(Event & Team Organizer)
Melissa Hilsabeck
(Event & Team Organizer)
Angela Racoosin
(Event & Team Organizer)
Kelly Torres
(Event & Team Organizer)

Pump It Up For Platelets! Cleveland, OH

\$6,313.00

Caroline & Ken Kruse
(Event & Team Organizer)
Suzanne & Keff Kerner
(Event & Team Organizer)
Nicole & Tyler Leffel
(Event & Team Organizer)

Pump It Up For Platelets! Orlando, FL

\$5,742.80

Sydney Avrick (Event Organizer)
Barbara & Peter Pruitt
(Team Organizer)

Pump It Up For Platelets! Cranberry Twp, PA

\$5,627.65

Lani Mozzoni (Event Organizer)
Kristen & Steve Tomczak
(Event & Team Organizer)

Pump It Up For Platelets! Ames, IA

\$5,075.00

Hayley & Nathan Shimanek
(Event & Team Organizer)

Running For Platelets - Key West Half Marathon

\$4,067.00

Cheri & Derek Zimmerman

Pedal 4 Platelets

\$3,722.66

Michael Tarantino, MD

Pump It Up For Platelets! Rancho Cucamonga, CA

\$3,340.00

Barbara Link (Event Organizer)
Destiny Owen (Event Organizer)

Cleveland Half Marathon

\$3,165.50

Alexandra Kruse

Pump It Up For Platelets! Sandgap, KY

\$1,555.00

Amanda Johnson

Archer & Greiner Bake Sale

\$1,141.25

Stephanie Zane, Esq.

Tri-Beta Bio Honor Society

\$825.00

Jennifer & Joseph Roberts

Lugo Fundraisers

\$773.00

Gloria Lugo & John Camera

Virtual Walk

\$440.00

Kristie Lyons

Sport Purple Day

\$438.21

Yvonne Molino

Parents Partner For Platelets

\$420.00

Kim & Robert Barber

St. Joseph's Secondary School Fundraiser

\$375.00

Julie Agius

Ayla Charness Fundraiser

\$357.18

Audrey & Jay Charness

Vineyard Christian School

\$319.50

Debi King

Pennies 4 Platelets

\$250.00

Bleeding & Clotting Disorders
Institute

Purple For Platelets Dog Agility

\$250.00

Jennifer Necker

Linda's Angels

\$245.27

Nicole Novello

Maple City Savings Bank

\$232.00

Pennies 4 Platelets

\$200.00

Cade Kleisner

August Challenge

\$169.27

Tammy Fassett

Tri Sigma Fundraisers

\$104.37

Sam Fallick

FASTRUBY

\$100.00

The Tillinghast Family

Lagree Fundraisers

\$100.00

Paula Lagree

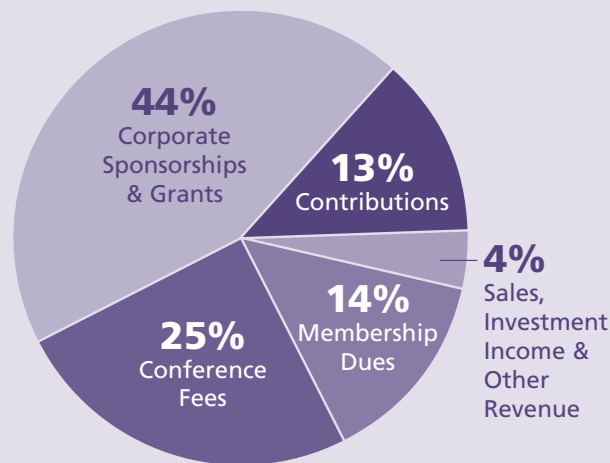
Bravelets

\$40.00

Linda Hanson

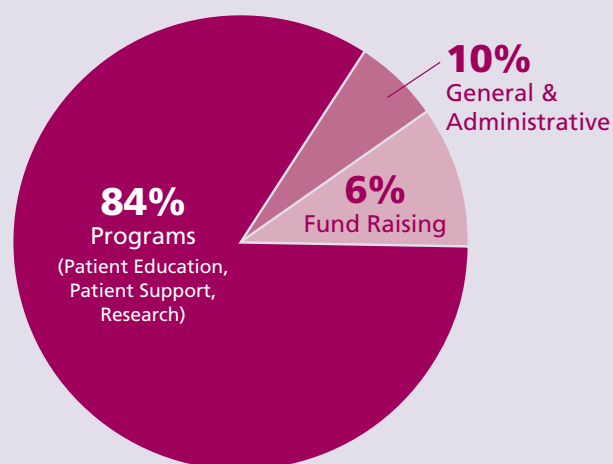
Contributions in 2016

Income Funding



Corporate Sponsorships & Grants	\$381,739
Contributions	\$116,265
Sales, Investment Income & Other Revenue	\$32,227
Membership Dues	\$120,235
Conference Fees	\$213,526
Total	\$863,992

How The Funds Were Used



\$0.84 of every \$1.00
goes directly to programs that support
and educate the ITP community.

Programs	\$681,109
General & Administrative	\$83,096
Fund Raising	\$48,799
Total	\$813,004
Net Assets at end of Year (accumulated)	\$1,144,816

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, 2016 and December 31, 2016.



"My son had ITP for three years. This was the first organization we found that offered hope and support. My son no longer has ITP but I feel forever indebted and hope to provide a contribution as often as I can."

– Stacy W.

Corporations & Foundations

AMGEN	Emergent BioSolutions
Bell Falla & Associates	Hill+Knowlton Strategies
Birny Mason, Jr. Foundation	Merck Foundation
Bristol-Meyers Squibb	Novartis Pharmaceuticals Corporation
Clinical Specialty Infusion Pharmacy	Octapharma
CSL Behring Biotherapies for Life	PCORI
Data Centrum	Protalex
Communications Inc.	Pulse CX
Diplomat	Rigel Pharmaceuticals, Inc.
	Schlesinger Associates

Matching Gift Companies

Amazon Smile Foundation	Give With Liberty Employee Donations
Bemis Company Foundation	IBM Employee Services Center iGive
The Benevity Community Impact Fund	The Janus Foundation
The Boeing Company Gift Matching Office	Merck Foundation
Chad Miles Romney Charitable Fund	PayPal Giving Fund
Charles Schwab	Pfizer Foundations Matching Gifts Program
Community Health Charities of North Carolina	PG&E Corporation Foundation
Costco	The Progressive Insurance Foundation
Fond du Lac Foundation	Truist
	YourCause, LLC



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

Madeline & John Hromyak
Louise Kittel
Barbara & Peter Pruitt, Jr.

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

Anonymous
Emily & Kris Kile

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

Jan & Steve Gardner
Kim & Rodney Hall
Joan & Richard Jordan
Stephanie & Mike Moran
Shirley & Peter Pruitt, Sr.
Karen Rosenbaum

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

Stuart Avrick
Cindy & Philip Ayliff
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Patricia & Bennett Henrikson
Noelle & Mat Heyman
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Ana & Eric Johnson
Diane & Robert Joseph

Caroline & Ken Kruse
Irene & David Kuter, MD, DPhil
David Lihani
Jenn & Andy Lindal
Mary Lou & James Lyons
Eleonore & Russell McCabe
The McGuirl Family
Irma & Daniel Miles
James Moe
Ethel & Alexander Nichoson Foundation
Jeanne & Dan Pinnell
Nancy & Michael Potthast
Patricia Pulley
Virginia Rennie
Jody & Jon Shy
Michael Tarantino, MD
Lois Umhoefer
Rich Webber
Elizabeth & Robert Welch
The Winter Family
Cheri & Derek Zimmerman

Supporters (\$1,000+)

Capital One Investing
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Mark Christopher Auto
Center

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Pediatrics
The Children's Rainbow Day
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Deborah Harlan
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Laurie & Brian McAleenan
Janet & William McAllister
Deanna McCarney

David Middleton
Monte Cello's of Cranberry
Patricia & Thomas Morris
Debra & Phillip Netz
Michael O'Connell
Ruby Ollie
Our Lady of Grace Catholic
Academy
Robert Pierce
Play & Learn Children's
Center
Stuart Plotkin
Jacqueline & Bruce Prescott
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Dee Anne Reynolds
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May Sai
Save On Beer
Theresa Schoenherr
Seneca Valley Jr. Football
Association & Cheer
Seneca Valley Soccer
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Vineyard Christian School
Ronald Virgin
Westfield Bank
Sarah Wijnen-Riems
Sherrie Winters
Margaret Zivelonghi

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Charrie Agraviador
Laura Alioto
Valentina Andren
Mark Andrews
Rebecca Antas
Sarah & Craig Antas
Darlene Aquilina
Roya Ara
Sara Armstrong
MaryLou Austin
Mona Aziz
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The Benevity Community
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Jacqueline Berger
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Kathryn Berry
Nancy & Chris Binford
Bob Bira
Marc Bjorkman

Contributions in 2016

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Bonnie Dowdy	Jackie Jordan	Patrick Nehls	Barbie Sauve	Hazel Wirstiuk
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*"The PDSA is an
incredible organization!
They have the top ITP
specialists and connect
people all across the
world."*

– Gen K.

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What our members are saying:

"From the bottom of our hearts, thank you, PDSA, for being a great resource of education and outreach during what was a very scary time in our lives."

– Gloria C.

"It is such good news that there are even more treatment options being developed. I am truly grateful for this association for their news and as a place for folks to express their concerns and experiences. Just knowing you are not alone is so uplifting. Thank you."

– Barbara M.

"Thank you for being there when it seemed that we were all alone."

– Donna W.



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