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.

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

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.

Caroline Kruse
Executive Director
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)

“\textbf{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

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.

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

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

Instagram Followers
   250+
   @PDSA_ITP

Twitter Followers
   900+
   @PDSA_ITP

YouTube Video Views
   70,000+
   PDSAorg

PDSA.org Discussion Forum Members
   7,600+

“Thank you. I’ve set my facebook feed so your posts appear first—our family values your efforts very much.”
   – Les T.

“I’m newly diagnosed at age 74. This website is a resource I will use frequently. Thanks.”
   – Yehuda C.

900
   Participants in PDSA’s Name Exchange Program

200
   Pages of Free Information

50,000
   Unique Visits per Month

70,000
   Total Visits per Month

3 Million
   Hits per Month

130
   Countries Represented

www.pdsa.org

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

US and International Calls/Emails per Year
   5,000
Education & Support Program Highlights

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).

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!

Atlanta Support Group

Members of the Atlanta, GA Support Group at the February 27th meeting
Education & Support Program Highlights

**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.”

**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!**

**Cayden K. proudly shows off his Buzzy®**

“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.

“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.

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

**57 kits distributed**

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

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Community Events & Outreach Highlights

ITP Conference 2016

“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

“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 teen session at ITP Conference 2016

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
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!
Community Events & Outreach Highlights

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

ORLANDO, FL

RANCHO CUCAMONGA, CA
ORANGE, CA
AMES, IA

CHICAGO, IL

CRANBERRY TWP, PA
SANDGAP, KY
CLEVELAND, OH
## 2016 Fundraisers/Walks

<table>
<thead>
<tr>
<th>Event/Location</th>
<th>Amount</th>
<th>Organizers/Coordinators</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pump It Up For Platelets!</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chicago, IL</td>
<td>$15,239.31</td>
<td>Emily Auterson (Team Organizer), Susan Frank (Event &amp; Team Organizer), Maria Soledad Ruiz (Team Organizer), Trish &amp; Paul Santaromana (Event &amp; Team Organizer), Jennifer &amp; Aaron Slad (Event &amp; Team Organizer)</td>
</tr>
<tr>
<td>Orange Co., CA</td>
<td>$7,536.00</td>
<td>Cathy &amp; Raul Aldama (Event &amp; Team Organizer), Leilani de Castro (Event &amp; Team Organizer), Melissa Hilsabeck (Event &amp; Team Organizer), Angela Racoosin (Event &amp; Team Organizer), Kelly Torres (Event &amp; Team Organizer)</td>
</tr>
<tr>
<td>Cleveland, OH</td>
<td>$6,313.00</td>
<td>Caroline &amp; Ken Kruse (Event &amp; Team Organizer), Suzanne &amp; Keff Kerner (Event &amp; Team Organizer), Nicole &amp; Tyler Leffel (Event &amp; Team Organizer)</td>
</tr>
<tr>
<td>Orlando, FL</td>
<td>$5,742.80</td>
<td>Sydney Avrick (Event Organizer), Barbara &amp; Peter Pruitt (Team Organizer)</td>
</tr>
<tr>
<td>Cranberry Twp, PA</td>
<td>$5,627.65</td>
<td>Lani Mozzoni (Event Organizer), Kristen &amp; Steve Tomczak (Event &amp; Team Organizer)</td>
</tr>
<tr>
<td>Ames, IA</td>
<td>$5,075.00</td>
<td>Hayley &amp; Nathan Shimanek (Event &amp; Team Organizer)</td>
</tr>
<tr>
<td>Key West Half Marathon</td>
<td>$4,067.00</td>
<td>Cheri &amp; Derek Zimmerman</td>
</tr>
<tr>
<td>Pedal 4 Platelets</td>
<td>$3,722.66</td>
<td>Michael Tarantino, MD</td>
</tr>
<tr>
<td>Rancho Cucamonga, CA</td>
<td>$3,340.00</td>
<td>Barbara Link (Event Organizer), Destiny Owen (Event Organizer)</td>
</tr>
<tr>
<td>Cleveland Half Marathon</td>
<td>$3,165.50</td>
<td>Alexandra Kruse</td>
</tr>
<tr>
<td>Sandgap, KY</td>
<td>$1,555.00</td>
<td>Amanda Johnson</td>
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<tr>
<td>Archer &amp; Greiner Bake Sale</td>
<td>$1,141.25</td>
<td>Stephanie Zane, Esq.</td>
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<tr>
<td><strong>Tri-Beta Bio Honor Society</strong></td>
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<tr>
<td><strong>Lugo Fundraisers</strong></td>
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<td></td>
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<tr>
<td><strong>Virtual Walk</strong></td>
<td></td>
<td></td>
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<tr>
<td><strong>Pump It Up For Platelets!</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Running For Platelets - Key West Half Marathon</strong></td>
<td>$438.21</td>
<td>Yvonne Molino</td>
</tr>
<tr>
<td><strong>Parents Partner For Platelets</strong></td>
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<tr>
<td><strong>Parents Partner For Platelets</strong></td>
<td>$940.00</td>
<td>Kim &amp; Robert Barber</td>
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<tr>
<td><strong>Ayla Charness Fundraiser</strong></td>
<td>$357.18</td>
<td>Audrey &amp; Jay Charness</td>
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<tr>
<td><strong>Vineyard Christian School</strong></td>
<td>$319.50</td>
<td>Debi King</td>
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<tr>
<td><strong>Pennies 4 Platelets</strong></td>
<td>$250.00</td>
<td>Bleeding &amp; Clotting Disorders Institute</td>
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<tr>
<td><strong>Purple For Platelets Dog Agility</strong></td>
<td>$250.00</td>
<td>Jennifer Necker</td>
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<tr>
<td><strong>Linda’s Angels</strong></td>
<td>$245.27</td>
<td>Nicole Novello</td>
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<tr>
<td><strong>Maple City Savings Bank</strong></td>
<td>$232.00</td>
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<tr>
<td><strong>Pennies 4 Platelets</strong></td>
<td>$200.00</td>
<td>Cade Kleinsner</td>
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<tr>
<td><strong>Tri Sigma Fundraisers</strong></td>
<td>$104.37</td>
<td>Sam Fallick</td>
</tr>
<tr>
<td><strong>FASTRUBY</strong></td>
<td>$100.00</td>
<td>The Tillinghast Family</td>
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<tr>
<td><strong>Lagree Fundraisers</strong></td>
<td>$100.00</td>
<td>Paula Lagree</td>
</tr>
<tr>
<td><strong>Bravelets</strong></td>
<td>$40.00</td>
<td>Linda Hanson</td>
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</tbody>
</table>

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Community Events & Outreach Highlights

www.pdsa.org | 11
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.

<table>
<thead>
<tr>
<th>Corporations &amp; Foundations</th>
<th>AMGEN</th>
<th>Emergent BioSolutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bell Falla &amp; Associates</td>
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<td>Hill+Knowlton Strategies</td>
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<tr>
<td>Birny Mason, Jr. Foundation</td>
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<td>Merck Foundation</td>
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<tr>
<td>Bristol-Meyers Squibb</td>
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<td>Novartis Pharmaceuticals Corporation</td>
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<tr>
<td>Clinical Specialty Infusion Pharmacy</td>
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<td>Octapharma</td>
</tr>
<tr>
<td>CSL Behring Biotherapies for Life</td>
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<td>PCORI</td>
</tr>
<tr>
<td>Data Centrum Communications Inc.</td>
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<td>Protalex</td>
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<tr>
<td>Diplomat</td>
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<td>Pulse CX</td>
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<tr>
<td>Octapharma</td>
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<td>Rigel Pharmaceuticals, Inc.</td>
</tr>
<tr>
<td>PCORI</td>
<td></td>
<td>Schlesinger Associates</td>
</tr>
</tbody>
</table>

**How The Funds Were Used**

- **84%** Programs (Patient Education, Patient Support, Research)
- **10%** General & Administrative
- **6%** Fund Raising
- **10%** General & Administrative

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

<table>
<thead>
<tr>
<th>Income Fundings</th>
<th>Corporate Sponsorships &amp; Grants</th>
<th>Contributions</th>
<th>Sales, Investment Income &amp; Other Revenue</th>
<th>Membership Dues</th>
<th>Conference Fees</th>
<th>Total</th>
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<tbody>
<tr>
<td>Income Fundings</td>
<td>$381,739</td>
<td>$116,265</td>
<td>$32,227</td>
<td>$120,235</td>
<td>$213,526</td>
<td>$863,992</td>
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**How The Funds Were Used**

<table>
<thead>
<tr>
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<th>Programs</th>
<th>General &amp; Administrative</th>
<th>Fund Raising</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programs</td>
<td>$681,109</td>
<td>$83,096</td>
<td>$48,799</td>
<td>$813,004</td>
</tr>
</tbody>
</table>

**Net Assets at end of Year (accumulated)**

| Net Assets at end of Year (accumulated) | $1,144,816 |

13 | 2016 Annual Report
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

Contributions in 2016

Supporters ($1,000+)
Capital One Investing
Cleveland Clinic
Mark Christopher Auto Center

Members & Supporters ($500-$999)
9 Dots Technology, Inc.
American Vending Sales
Ames Area USBC
Arch & Greiner
Bleeding & Clotting Disorders Institute
Julie Bremser & Carl Necker
Thomas V. Callaghan, P.C.
Joan & Doug Cannam
Carol Stream Dental Associates
Anna & Bosco Chao
Charitable Realty
Columbiettes of Monsignor Cafiero
Magda El-Nokaly
Ann George
Brenda Gubrud
Chris Gunder
Paula & Thomas Huntzinger
Anne & Pitkin Johnson
Kentucky Turf Company, Inc.
Michael Lang
Joni & Alan Lichtin, MD

Circle of Hope ($1,000-$1,999)
Individuals
Stuart Avrick
Cindy & Philip Ayliff
Kenda & Brian Bamesberger
Dail Barbour
Mary & James Benvenuto
Amita & Ranjive Bhalla
Brendan Cameron
Charlotte Cunningham-Rundle, MD & James Bussel, MD
Mr. & Mrs. William Deaver, III
Rachel & Patrick English
Robert Feiner
Allison & Keith Flowers
Jim & Benjamin Grimes
Kristin Henrikson & Jon Brandt
Patricia & Bennett Henrikson
Noelle & Mat Heyman
Sherrill Hudson
Ana & Eric Johnson
Diane & Robert Joseph

Circle of Hope ($1,000-$1,999)
Individuals
Barbara & Peter Pruitt, Jr.

Members & Supporters ($100-$249)
Members & Supporters
($250-$499)
Carol Stream Dental Associates
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Sherrill Hudson
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
Irmia & 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

Dan Lyons
Katharine McCleary
Thomas Mitchell
NGS Printing, Inc.
Oak Tree Wealth Partners
Lorraine Passoni
Susan & Dale Paynter
Rosen Family Fund
Debbie & Thomas Serra
Louisa Stead
Titan Baseball Academy
Tri-Beta Biological Honor Society
Sonia & Jeremy Vandama
Stanley Winer

Members & Supporters
($250-$499)
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Patricia & Bennett Henrikson
Noelle & Mat Heyman
Sherrill Hudson
Ana & Eric Johnson
Diane & Robert Joseph

Members & Supporters
($100-$249)
Ralph Acevedo
John Adams
Charrie Agraviador
Laura Alioto
Valentina Andren
Mark Andrews
Rebecca Antas
Sarah & Craig Antas
Darlene Aquilina
Roya Ara
Sara Armstrong
MaryLou Austin
Mona Aziz
Mitch B.
David Bacon
Caroline Bagguley
Athena & Michael Baglio
Chris Banko
Tracy Banks
Jan Bauer
Jeffrey Bauman
Judith Beattie
Vicki & Charles Beloian
The Benevity Community Impact Fund
Jacqueline Berger
Morris Bergstein
Kathryn Berry
Nancy & Chris Binford
Bob Bira
Marc Bjorkman
Contributions in 2016

Barbara Blackburn
Charlotte Blankfield
Aija Blitte
Mona Bobrow
John Bouson
Michael Bouson
Sherry & William Bragg
Adam Brand
Andrea & C. Ellis Brigman
Jane Bronson
Andrew Brown
Dorothy Brown
Anne Burke
Mary & Peter Cagle
Pamela Cameron
Tammi Cammauf
Miki Carlton
Jan Carmean
Michael Carpenter
Donna Carter
Barbara Chao
May & Thomas Chin
Kendra Chiprich
Mary & Paul Chmiel
Lee Chota
Kay Chow
Kenneth Christensen
Judy Christiansen
Walter Chubrick, Jr.
Douglas Cines, MD
Sharon Cisco
Barbara & Gib Coats
Regina Cochran
Ellen Cook
Joan & Joseph Coppolino
Costco Corporate Office
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“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.”
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