IDF 2017 National Conference: June 15-17
Community in Action - Be a Part of It!

Join us for the IDF 2017 National Conference in Anaheim, CA, our 9th National Conference, June 15-17, 2017! The Immune Deficiency Foundation (IDF) brings together the community every other year for a three-day conference, the world’s largest gathering of people living with primary immunodeficiency diseases (PI). From physicians to nurses to specialized life management experts, individuals and families are presented with an unsurpassed opportunity to network with those on the cutting edge of research and treatment. This year, we will have something for everyone. Whether you have attended in the past or this is your first conference, there will be plenty of sessions for you to enjoy!

Now more than ever, the impact of the IDF community is critical. Together, we can create a better future for those living with PI. This conference will focus on Community in Action, as we examine how far we’ve come as a rare disease community and how much more we can accomplish in the future.

Visit the IDF 2017 National Conference website for complete details, registration information and ongoing updates as June approaches: www.idfnationalconference.org.

Conference Highlights

Healthcare and Life Management Presentations

Choose from almost 40 sessions to attend! World-renowned healthcare professionals will share their time and expertise to help you better understand and manage your PI. Learn from life management professionals who will provide you with ideas you can incorporate into your daily life. Meet and talk with others from the PI community, and share your experiences throughout the weekend.

continued on page 2

Photos from IDF 2015 National Conference

 Raises Over $1.1 Million
Details on page 4

This newsletter is sponsored by an educational grant from Grifols.

The national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.
IDF Order of the Zebra

Become an IDF Order of the Zebra Member and Have Your National Conference Registration Reimbursed

Members of the IDF Order of the Zebra are incredible individuals who raise $1,000 or more for the IDF Walk for Primary Immunodeficiency. The funds raised by members of the Order make an enormous impact on IDF’s ability to serve people with PI. If you were a 2016 member of the Order, you automatically qualify for a refund of your conference registration fee.

If you would like to become a 2017 member of the Order and earn your conference registration refund, go to: www.walkforPI.org. Register for the walk of your choice, and start fundraising! Once $1,000 has been recorded on your personal fundraising page (not your team page), IDF will automatically be notified.

In order to qualify as a 2017 member, $1,000 in donations must be recorded on your page by June 8, 2017. Reimbursements will be processed approximately two weeks after the conference concludes. For more information, please contact us: walk@primaryimmune.org.

Silent Auction: Calling All Zebras - Donate an Auction Item

Items for the auction are donated by generous and resourceful members of our community. Successful past items have ranged from custom-made quilts and electronic gadgets, to family-fun gift baskets and of course anything with zebra stripes.

If you can donate an auction item, go to www.biddingforgood.com/THINKZEBRA, and click on “Donate Items” to learn more.

If you need inspiration or have any other questions about the auction, contact IDF: 800-296-4433 or development@primaryimmune.org.

IDF 2017 National Conference Highlights

Welcome to California Reception
Help us kick-off the IDF 2017 National Conference on Thursday night! Hear what’s planned for the conference, and mingle with other members of the PI community. California casual attire, bright colors and cool shades are encouraged! See the grand opening of the Exhibit Hall, and enjoy light hors d’oeuvres, a fun time and a feeling of comradery. Sponsored by Shire.

IDF Zebra Gala
Celebrate the 9th IDF National Conference with a festive Friday night! Enjoy great music, food, libations, recognitions, and, of course, a touch of zebra. Take part in our fabulous Silent Auction, which will kick off the eventful evening with relaxed, quiet bidding on a variety of wonderful items donated by the IDF community. Attire for the night is festive, black and white—as always, zebra stripes are welcome. Sponsored by CSL Behring.

Closing Session & IDF Family Night at Disney
On Saturday evening, let’s come together one final time for the Closing Session. Then we will enter the magical world of Disney. IDF Family Night at Disney gives conference attendees an evening pass to enjoy attractions, entertainment, dining, events and tours in Anaheim’s happiest theme park.

IDF Exhibit Hall
Leave room in your information-packed conference schedule to visit the Exhibit Hall! Here, companies and organizations can show you the newest products and services available to the PI community. Just like in the past, visiting all the participating exhibits can put you in the running to win an iPad!

IDF Youth Program
We’re educating and inspiring tomorrow’s future today! The IDF Youth Program, available Friday and Saturday, offers exciting events exclusively for children and teens with PI or have an immediate family member with PI. Programs include: Childcare (6 months to 4 years), Kids Club (5 to 9 years), Tween Scene (10 to 12 years) or the Teen Program (13 to 18 years). An off-site trip for ages 5 to 18 to Discovery Cube is planned for Saturday. Be sure to register your children in advance—onsite registration not available.

Special Symposia
This year, IDF will offer three special symposia, which will include presentations from experts in the respective fields and opportunities for attendees to network with other individuals and families.

Special Chronic Granulomatous Disease (CGD) Symposium
Sponsored by Horizon Pharma.

Special Severe Combined Immune Deficiency (SCID) & SCID Variant Symposium
Sponsored in part by the IDF SCID Initiative and Leadiant Biosciences.

Special Wiskott-Aldrich Syndrome (WAS) Symposium
Sponsored in part by the Wiskott-Aldrich Foundation.

The special sessions are available Thursday and Friday, and participants can attend general sessions Friday after the symposia ends and all day on Saturday.

Professional Medical Education Program
At the IDF 2017 National Conference, clinicians have a special opportunity to learn the latest information about PI from expert immunologists during the Clinical Immunology Society (CIS) Professional Medical Education Program: Updates in Primary Immunodeficiency Disease for the Practicing Immunologist. This program is offered Saturday during conference hours.

New Sessions
In 2017, we will feature several new sessions:
• Caring for the Caregiver
• Clinical Trials: What to Consider
• For Parents: Parenting a Teen or Young Adult Diagnosed with PI
• NK Cell Deficiency
• Unspecified Combined Immunodeficiencies with Autoimmunity & Infection

Online registration is available at www.idfnationalconference.org/register. Early registration rates are available until Monday, May 1, 2017.

Learn more about the IDF 2017 National Conference at: www.idfnationalconference.org.

IDF 2017 National Conference Sponsors

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CSL Behring
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The Impact of IDF Education Meetings

People who attend IDF Education Meetings leave with a better understanding of primary immunodeficiency diseases (PI), and that is our goal. IDF carefully plans each meeting to provide individuals and families living with PI valuable presentations from experienced healthcare professionals and life-management experts. Held throughout the U.S., these meetings are unique opportunities for people with PI and those who care for them to learn more about the diseases and to make meaningful connections with others in the PI community.

“I now much better understand primary immunodeficiency.”

– 2016 Meeting Attendee

In recent years, IDF has made a commitment to further enhance and increase the number of local meetings. We partner with healthcare professionals nationwide to reach more people and enrich the content of the meetings. At each meeting, IDF staff members and volunteers coordinate the day’s activities and answer questions, and sponsor exhibits allow attendees to learn more about products and services.

“Every segment of the meeting was thorough, well informed and thought provoking.”

– 2016 Meeting Attendee

In 2016, IDF held 27 Education Meetings, reaching 1,764 people, who learned about diagnosis, treatment options, allergies, immunizations, and more. After morning sessions, presenters then serve on a panel to answer questions from those in attendance. Among the meetings held, we also include IDF Family Conference Days, which are Education Meetings that include youth programs.

Aside from gaining valuable information, these meetings make an impact on those who attend. For some, it is the first time they meet someone else with PI. Individuals are encouraged to share their stories and create connections that they can’t do anywhere else.

2017 will be no different. We are planning 27 Education Meetings, and it is our hope to reach as many individuals and families as possible and to help them better understand PI.

For upcoming meetings, check the IDF Calendar of Events at: www.primaryimmune.org/events-calendar. The calendar is updated regularly as meetings are scheduled.

IDF Education Meetings are supported by charitable donations from:

AbbVie, CSL Behring, Grifols, Shire
AmerisourceBergen Corporation, Octapharma
ADMA Biologics, Bio Products Laboratory, Horizon Pharma, Kedrion Biopharma
Accredo Healthcare, Coram CVS Specialty Infusion Services

2016 Education Meetings Stats

1,764 Attendees
114 Presenters Volunteered Their Time & Expertise
27 Education Meetings

2016 Meeting Locations:
Albuquerque, NM
Atlanta, GA
Aurora, CO
Bellevue, WA
Chandler, AZ
Charlotte, NC
Cleveland, OH
Columbus, OH
Dallas, TX
East Lansing, MI
Edina, MN
Fort Lauderdale, FL
Henderson, NV
Houston, TX
Indianapolis, IN
Iowa City, IA
Jackson, MS
Kansas City, MO
Linthicum Heights, MD
Los Angeles, CA
Northbrook, IL
New York, NY
Omaha, NE
Philadelphia, PA
San Diego, CA
Sarasota, FL
St. Louis, MO

IDF 2017 National Conference Sponsors
In 2016, IDF Walk for Primary Immunodeficiency brought together more
than 4,000 participants on more than 400 teams across the country,
uniting the PI community to help create a better future for those living with
these rare, chronic diseases. With the help of our walkers, hundreds of
volunteers and our generous sponsors, we raised more than $1.1 million!
Funds raised support critical IDF programs, including the IDF Research
Grant (see page 5 for details).

So thank you to all those who joined us in 2016 and made IDF Walk for
PI a continued success!

Top Teams

The following teams went above and
beyond bringing in the highest totals
of the season:

National Walks
Atlanta - Holly’s Friends & Family
Boston - Love Wins
Charlotte - Carolina Zebra’s
Chicago - Gus’s Team
Tyrannosaurus Rex
Cleveland - Lucas’s Stars
Fort Lauderdale - Zebra Crossing
Houston - Megan’s Herd
Los Angeles - Team Justin
Minneapolis - Zebras in Tiaras
New York City - Zebras in Tiaras
Philadelphia - Team DISCOvery
St. Louis - Team Taylor

Community Walks
Blountville – Team Elizabeth
Omaha – Vada Strong

Order of the Zebra
Members

Some walkers went the extra mile—82
participants raised $1,000 or more!
For a complete list of 2016 members,
go to: www.walkforPI.org.
IDF Walk for PI 2017

We’re already looking to the future—will you join us in 2017? Create a team for IDF Walk for PI, and walk with us to help create a better future and, one day, cures.

Registration for IDF Walk for PI 2017 Now Open!

2017 Locations
Atlanta, GA - 10/28
Boston, MA - 10/1
Chicago, IL - 10/22
Cleveland, OH - 9/24
Dallas, TX - 11/11
Fort Lauderdale, FL - 11/19
Kansas City, MO - 10/8
Los Angeles, CA - 11/5
New York City, NY - 10/22
Philadelphia, PA - 10/15
St. Louis, MO - 10/15
Tampa, FL - 11/18

Don’t see your city? We still need your help to create a better future.

Organize a walk in your city with a Community Walk or participate at your own pace by creating an online team for the Nationwide Virtual Walk.

For more details, please contact us: walk@primaryimmune.org.

Learn more at www.walkforPI.org

First IDF Research Grant Awarded from IDF Walk for PI Funds

IDF Walk for Primary Immunodeficiency unites the community to help create a better future for people with PI. And part of creating a better future is more research. Because of the success of IDF Walk for PI, the IDF Research Grant has been established to support well-defined research projects that have a specified benefit for improving the treatment, health, disease management or diagnosis of people with PI.

In 2016, IDF awarded its first grant to Dr. Sonia Sharma, an Assistant Professor in the Division of Cellular Biology at La Jolla Institute for Allergy and Immunology and Director of the Functional Genomics Center in La Jolla, CA. Dr. Sharma’s research focuses on using unbiased, genome-scale RNAi and CRISPR/Cas9 approaches to further understand type I interferon signaling and works to define the key genetic mechanisms regulating cellular innate immunity, and determine how they impact human health and disease. Dr. Sharma’s research grant application focused on the link between XMEN disease and potential defects in innate immunity. Individuals with XMEN immunodeficiency are prone to persistent infections from various bacteria and viruses—the impact of this disease on the immune system is not yet fully understood.

“Every penny is going into the study of the disease,” says Dr. Sharma. She intends to use the grant to further advance the research and lead to new understandings and treatment options to improve quality of life.

More IDF Research Grant awards will be made in 2017!

Thank you to everyone who participated in IDF Walk for PI and raised funds to help support research of these rare, chronic diseases and to help to create a better future for those living with PI.

To learn more about the IDF Research Grant, go to: www.primaryimmune.org/idf-research-grant-program.
Advocating for Continued Access to Care

For many years, IDF has been on the forefront of public policy issues affecting the primary immunodeficiency (PI) community, but now more than ever we must remain vigilant and ensure that people with PI have access to the medication and treatments they need to live healthy lives. Recent federal actions have brought an urgency to issues critical to the PI community, and we will be contacting you periodically about reaching out to the Administration and to your Members of Congress to ensure people are able to continue to receive the care they need.

Congress: Don’t Repeal without Replacing the ACA

Congress is working right now to develop legislation that will replace the Affordable Care Act (ACA). It is imperative to let your Representatives and Senators know that they must not repeal the ACA without an immediate plan to ensure that people keep the protections they currently have. No matter your political views, changes to the ACA can affect everyone, and we want to make sure our community is protected.

How Changes to the ACA Affect People with Primary Immunodeficiency

People with PI and other rare, chronic conditions rely on protections established by the ACA. We cannot lose the gains we have made in healthcare access. Congress needs to know that they must maintain current protections of the healthcare system that:

• Ensure access to affordable, comprehensive insurance and necessary treatments for people with pre-existing conditions;
• Prohibit annual and lifetime caps on insurance coverage; and
• Continue limits on annual out-of-pocket costs.

Make sure to sign up for IDF Action Alerts, and make your voice heard to ensure access to treatment for everyone in the PI community: www.primaryimmune.org/action-alerts.

Also, we encourage you to share this message with your friends on social media and post it on your representatives’ social media accounts.

Saving SCIG on Medicare

In December, Congress passed and the President signed into law the 21st Century Cures Act. This bill will bring healthcare innovation infrastructure into the 21st Century, providing necessary resources to researchers to continue their efforts to uncover the next generation of cures and treatments. While this bill will do many positive things for those with rare, chronic diseases, one part of the law may have a negative effect on people with PI who receive subcutaneous immunoglobulin therapy (SCIG) and are on Medicare.

Effective January 2017, the bill calls for the reduction in the reimbursement for infusions using durable medical equipment, such as pumps for SCIG. Specialty providers that provide SCIG, as well as the equipment, training and monitoring of patients, are struggling with this reimbursement reduction, and some may not be able to afford to continue providing SCIG to Medicare beneficiaries.

IDF recognized the potential negative impact on the PI community of such a reduction in reimbursement and worked hard to add reimbursement for professional services, training and monitoring to the legislation. IDF was successful in having additional reimbursement for those services.

However, at the last minute, Congress delayed implementation of our provisions until 2021. We are now concerned that some specialty pharmacies may at some point in 2017 drop their SCIG services to Medicare beneficiaries. IDF is currently working with Congress to provide a legislative fix that would accelerate the reimbursement for professional services, training and monitoring as soon as possible. IDF will keep the community informed and will be asking your help through IDF Action Alerts and social media. When there is a call to action, please respond and contact your legislators.

Questions about public policy issues that affect the PI community?
Call 800-296-4433, or submit your questions through Ask IDF: www.primaryimmune.org/ask-idf.

Taking Care of the Next Generation

Ensure IDF Resources for Years to Come

Think back to those first days after you or your loved one’s diagnosis and what it felt like to have a disease you knew nothing about. Do you recall feeling isolated and scared?

Now, remember the relief you felt when you discovered IDF, an organization with resources you needed and a community that supported you. You finally had answers. You finally found people who understood.

You can make sure the next person diagnosed with a primary immunodeficiency has the resources and the support they need. If you feel IDF has helped you in any way, now is the time to make a gift.

Please use the enclosed envelope to make your donation or go online to: www.primaryimmune.org/give.

Thank you!
Early on, IDF recognized the importance of learning from the experiences of people with primary immunodeficiency diseases (PI) and since 1995 has conducted surveys to gain a better understanding of how the lives, treatment and diagnosis of those with PI can be improved. With topics ranging from treatment and disease specifics to health insurance, women’s health and more, these surveys take your individual experiences to help the entire community.

What We’ve Learned

The most important aspect of the surveys is hearing from you, an individual or a caregiver who is living day in, day out with a chronic, rare condition. Patient-reported outcomes (PROs) are increasingly recognized as an important part of improving the quality of care in clinical settings, meaning more often, healthcare professionals are looking at your input to help determine how to handle and manage your health.

In 2016, IDF conducted a survey using the Patient-Reported Outcomes Measurement Information System (PROMIS), called PROMIS-29, as part of the IDF ePHR. Using short questionnaires, the PROMIS-29 assesses seven health categories: Physical Function, Pain, Interference, Fatigue, Depression, Anxiety, Sleep Disturbance, and Ability to Participate in Social Roles. More than 300 adults participated. Compared to the general population, people with PI reported higher anxiety, depression, fatigue and pain interference along with lower physical function and social roles.

Released in 2013, the National Treatment Survey and SF 12, a survey that is a valid measure of physical and mental health, taught IDF what experiences our community faces with immunoglobulin (Ig) replacement therapy, including intravenous immunoglobulin (IVIG) and subcutaneous immunoglobulin (SCIG). That data told us:

- Proper diagnosis and therapy can be a tremendous benefit to those with PI. 61% of those who were diagnosed with a PI and currently on Ig therapy reported their general health as good or better, compared to only 15% who reported their health as good or better prior to diagnosis and treatment for their PI. 55% of those surveyed were using IVIG, and 45% were using SCIG.

- Asthma (55%), Arthritis (50%), Autoimmune Condition (37%), Digestive Disease (34%), and Malabsorption/Diarrhea (29%) were among the top five chronic conditions reported by those receiving Ig in the past 12 months.

- People on IVIG were less likely to report being bothered by their therapy than those on SCIG. Both people on IVIG and SCIG are equally satisfied with their chosen Ig product at 77% each.

The 2012 Primary Immunodeficiency and Women’s Reproductive Health survey revealed that from the 701 women who were evaluated, over one-third (34%) stated that having a PI had an impact on their decisions to have or try and have children. Compared to U.S. national statistics, the overall reported fertility rate was lower whereas the birth success rate was comparable.

A 2012 National Patient Survey told us that 9 out of 10 individuals reported repeated, serious or unusual infections prior to diagnosis and that around half of all people with PI are not diagnosed until they are 30 years of age or older. In this survey, we found that our community reported only two-thirds who felt their current health was good, very good or excellent. However, most stated their health causes no limitations or slight limitations on work, play and other activities. Nonetheless, the general health, activity limitation and hospitalization rates for people with PI were measurably poorer than the general public. The long-term outlook for most individuals with PI, while good, could be greatly improved by earlier diagnosis and better access to appropriate care and treatment, a fact that has not changed in 2017.

Your Individual Experiences Help the Entire Community

What IDF Surveys Have Taught Us

Your participation in IDF surveys is crucial. Your voice will not be heard if you do not participate. When you receive an invitation to take an IDF survey, we encourage you to do so. We want to ensure that each and every member of the PI community is heard.

To further take part in research, sign up for IDF ePHR and IDF PI CONNECT. Through these innovative tools, you can track your health and give researchers insight into your experiences living with PI. To learn more, go to: www.idfephr.org.

For more information about IDF research initiatives, contact us: idfresearch@primaryimmune.org.
April: National Primary Immunodeficiency Awareness Month

World PI Week, April 22-29

Since primary immunodeficiency diseases (PI) are rare, not many outside the PI community know what they are. This can be frustrating for those who are living with one of these chronic diseases. This April, help promote awareness! Your efforts can lead to earlier diagnosis and appropriate treatment, not to mention a better understanding of these conditions. And IDF has the resources to help you. Make it fun, get creative and help increase awareness of primary immunodeficiency!

THINK ZEBRA! Wear Zebra!

In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras,” and are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra. People with primary immunodeficiency diseases are the zebras of the medical world. So IDF says THINK ZEBRA!

This April, wear your favorite zebra attire and encourage your friends, family and coworkers to do the same. Take photos and share them with us using IDF Friends, Facebook, Twitter or Instagram, and send them to: idf@primaryimmune.org.

Share Informational Materials – Use the IDF “Learn More” Poster

We developed the Learn More – IDF Awareness Poster to lead people and family members to IDF to use our services and innovative materials. You can start in your community! Are you a member of Facebook groups or other online communities related to PI? Share the poster with them! You can download or order awareness posters, information cards and IDF publications to distribute at libraries, clinician’s offices, infusion centers, home healthcare companies, places of worship, school and other civic organizations.

For healthcare professionals promoting awareness, it’s essential that individuals and families connect directly with IDF to make sure they receive updates, so please display our Learn More poster in your offices and direct your community to contact IDF directly!

No matter how or where you decide to get your message across, IDF has the resources you need. Download materials at: www.primaryimmune.org/awareness.

Contact Local Media

You can tell your story to the local media with the help of our Media Kit, which includes steps on how to go about contacting the media, sample letters and press releases, FAQs about PI, and other helpful information to use when reaching out to your local media. A good human-interest story is an easy pitch, so contact your local reporters and share your story!

World PI Week: April 22-29

IDF joins the efforts of organizations across the globe to promote awareness of primary immunodeficiency diseases during World PI Week, April 22-29. IDF participates in worldwide initiatives with the objective to Test, Diagnose and Treat! For more information about World PI Week, visit: www.worldpiweek.org.

Show Us What You Did & Take a Selfie - #PIawareness

Already have plans to promote awareness in your community? Take a selfie (or #selfie if you’re a relative of TZ) to show off your work or zebra attire. Submit stories and pictures for social media, the IDF Blog and/or the IDF ADVOCATE newsletter. Share with us on Facebook, Twitter, Instagram, IDF Friends, and email us at idf@primaryimmune.org.

Spread the Word on Social Media

Using social media is one of the best ways to share facts and information about PI with many people at once. Here’s what you can do:

• Using IDF Friends, connect with others living with PI and find individuals and families in your area to organize efforts: www.idffriends.org

• Create a video and share you story with your own IDF Reel Stories: www.primaryimmune.org/idf-reel-stories

• Like IDF on Facebook, follow @idfcommunity on Twitter and Instagram and encourage your friends and followers to do the same! Try using these hashtags: #primaryimmune #Plawareness #thinkzebra

• Share facts about PI throughout the month. Find sample posts here: www.primaryimmune.org/awareness

• Download the IDF Awareness Month profile and cover photos at: www.primaryimmune.org/awareness
Quilting for a Cause
How One Member of the IDF Community THINKS ZEBRA! and Raises Awareness of Primary Immunodeficiency Diseases

Visitors to the IDF conference room immediately notice a very unique decoration on the wall—a hexagonal shaped quilt with 19 different zebra patterns. Yes, 19 different zebra patterns! This incredible quilt not only illustrates THINK ZEBRA!, but it also symbolizes the strength of those living with primary immunodeficiency disease (PI). Janet Purlee, a talented member of the IDF community, made the wonderful quilt and donated it to IDF. Naturally, we had to learn a little more about her and share her story.

Janet was diagnosed with Hyper IgM in April 2004. For years before her diagnosis, she lived with frequent infections and chronic illnesses. Now 58 years young and retired after 30 years as an Occupational Therapist, Janet is actively involved with a children’s program and acts as a “Hopekeeper” support group facilitator, where she helps others in need who live with chronic illness and pain. Her true passion, however, is designing and creating quilts.

“I began quilting at the age of 13,” Janet says, “I was not the typical young teenager, flirting with boys, but instead preferred the company of a group of older ladies’ at my church who taught me how to quilt.” In her lifetime, Janet has completed more than 20 quilts and has many more in the works. In fact, Janet is currently working on a book entitled “Mosaic Comforts” that displays each quilt and the story behind them.

“The support from IDF will definitely be a part of my book,” explains Janet. “I am so thankful for all the personal support and helpful educational information I received from IDF.” Being a “zebra” has helped many, like Janet, get through tough moments, including lengthy IVIG treatments, medical procedures and the daily struggles of living with a chronic illness. When asked why she made IDF a quilt, Janet simply said, “I wanted to give back in the way I know best… making an art quilt!”

Janet actually made two THINK ZEBRA! inspired quilts. The first one was created for a quilt challenge display called “Wild Thing” that encouraged the use of fabric that had barbed wire fences on it. Janet took this opportunity to portray the image of zebras in the wild, free from the constraints of chronic conditions, like PI. One of the blocks is the THINK ZEBRA! logo, featuring the Foundation’s mascot TZ the IDF Zebra, which enables her to promote awareness for the entire PI community at various quilt shows.

“I often think of TZ when the needle is being inserted… or I have to undergo other difficult or painful medical procedures,” says Janet, who often works on her quilts during her IVIG treatments. When it comes to making her quilts, it can be a time consuming project, which can vary depending on her health and the complexity of the quilt design.

Standing strong in the face of a rare, difficult illness, like PI, is what Janet believes being a zebra is all about. When asked what advice she has for other members of PI community to show they are “zebra strong” and help to promote awareness, Janet says, “Learn as much as you can about PI. Be the best advocate for yourself.” She also reminds the community that everyone should live life to the fullest every day and in every way.

“I hope that others looking at my quilts will be inspired to get in touch with their creative talents and share their abilities and their stories.”

IDF extends sincere appreciation to Janet for her extremely generous and thoughtful contribution. The quilt is now a cherished part of the IDF office.

If you have a story about living with PI and want to share it, go to: www.primaryimmune.org/share-your-story.
IDF always encourages questions from the community—whether submitted online or asked at our educational meetings across the country. We took a few questions we’ve received recently and asked the IDF Nurse Advisory Committee to answer them.

**What is the difference between CVID and Hypogammaglobulinemia?**
Common Variable Immune Deficiency (CVID) is characterized by very low levels of immunoglobulins, so it is a form of hypogammaglobulinemia. In some people with CVID, there is a decrease in both IgG and IgA; in others, all types of immunoglobulins (IgG, IgA, IgM, and IgE) are decreased. People with CVID are treated with immunoglobulin (Ig) replacement therapy. Hypogammaglobulinemia is a descriptive term referring to lower than normal levels of immunoglobulins and antibodies in the blood. Hypogammaglobulinemia is seen in many primary immunodeficiency diseases but also may be seen in protein-losing states.

**Does immunoglobulin (Ig) replacement therapy help so much that the frequency of infusions could diminish over the years?**
No, the immunoglobulins infused only remain in the body for a certain number of days, even if you have been on Ig replacement therapy for many years. For intravenous immunoglobulin (IVIG), within 3-4 weeks your body will consume most of the infused immunoglobulins at which time another infusion must be given. For subcutaneous immunoglobulin (SCIG), infusions are given weekly to monthly and must follow the same infusion schedule to maintain adequate functioning immunoglobulins.

**Can someone with PI donate blood?**
People with primary immunodeficiency diseases may donate blood if they are not receiving immunoglobulin therapy and if they are free from infection. People receiving immunoglobulin (either intravenous or subcutaneous) cannot donate blood or plasma while they are receiving therapy. According to the American Red Cross, you cannot donate for 12 months after receiving a blood product, such as immunoglobulin therapy, which is derived from blood plasma.

**What can be done to strengthen the immune system?**
The immune system is precisely that—a system, not a single entity. To function well, it requires balance. There is still much that researchers don’t know about the intricacies and interconnectedness of the immune response. For now, there are no scientifically proven direct links between lifestyle and enhanced immune function.

Presently, the only medical therapy that, in effect, “boosts” your immune system is Ig replacement therapy, which is only indicated for people with PI who have antibody deficiencies. Other diagnoses, such as Chronic Granulomatous Disease, may benefit from interferon injections to help their infection susceptibility. Your healthcare provider is the best person to consult about the appropriate therapies for your specific PI.

Following general good health guidelines can help keep you healthy. Every part of your body, including your immune system, functions better when bolstered by healthy living strategies, such as good nutrition, hygiene, sleep and exercise.
IDF Legacy Society

IDF is fortunate to have members of our community who philanthropically support us in many different ways. Some support us through the walks. Some make end-of-year gifts. Some of the younger ones even create lemonade stands! Each of those gifts helps us advance our mission. There is, however, one type of gift that helps us do even more for our community: a legacy gift.

Everyone should have a will. It’s the way that you can make your intentions and values clear leaving nothing to chance. It’s a way that you can make a mark and create a legacy that truly impacts the next generation. IDF has been fortunate in that people have chosen to name IDF as a beneficiary of their will or other estate plans. Those commitments, when ultimately received, are transformative for what IDF can do for the PI community.

If you haven’t created a will or haven’t reviewed your plans in recent years, please consider the transformative effect that you could have by naming IDF as a beneficiary of your will, life insurance policy, or other estate plans. If you do, IDF will gratefully recognize you as a member of the IDF Legacy Society.

If you have already chosen to include IDF in your financial or estate plans, please let us know so we can properly thank you. To let us know about your plans or to learn more about the IDF Legacy Society, please contact John G. Boyle at: jboyle@primaryimmune.org.

Remembering Members of Our Community

To remember members of our community who have passed away, IDF has created a perpetual plaque. Individuals with PI, parents, medical professionals and caregivers can be honored through inclusion on this plaque. It is a tribute to memorialize those who were an important part of our community and is free of charge.

Some of the most recent additions include Nick Faulkner, Savannah Goodman, John Guntkowski, Diana Johnson, Samantha Penn and Kay Stephens.

If you would like to submit a name to be included on the memorial plaque, please e-mail that person’s first and last name along with a little about their life to: development@primaryimmune.org.

WITH GRATITUDE MEMORIAL GIFTS
October 18, 2016 – January 17, 2017

Erik Anderson
Bernard Arseneau
William Bausman
Charles Bihn
Bud Calkins
Jacob Domka
Erica Drap
Nicholas Faulkner
Paul Feinberg
Daniel Fratto
Merritt Geiger
William Geisler
Maureen Godfrey
Delores Goldsmith
Savannah Goodman
Stuart Haslip
Rohan Karer
Jennifer Lipschultz
Lela Locklin
Kristin Martin
James Mouzon
Samantha Penn
Julia Perlander Christiana
William Pippin
Elizabeth Ponder
Donna Pregmon
Donald Schrock, Jr.
Margaret Shekleton Roth
Martin Sue
John Tan
Grant Tressler II
Darlene and William Verona
Annette Viles
Jerry Voyles
Eric Weintraub
Jon Westmoreland
Thomas Whalen

All donations help IDF improve the diagnosis and treatment of individuals with primary immunodeficiency diseases through advocacy, education and research.

If you would like to make a donation, please go to www.primaryimmune.org/give or contact us:

Phone: 800-296-4433 or 410-321-6647
Monday - Friday, 9 am - 5 pm (ET)
E-mail: development@primaryimmune.org