Immune Deficiency Foundation
PI Awareness Month & World PI Week 2016 - Report
PI Awareness Month & WPIW 2016

This April, the Immune Deficiency Foundation (IDF) promoted National Primary Immunodeficiency Awareness Month in the U.S. in conjunction with World PI Week (WPIW), April 22-29, through the following:

• CIS & IDF Partnership
• IDF Meetings & Events Across the U.S.
• National Volunteer Week
• IDF Plasma Partners Program
• IDF Newsletter & e-Newsletter
• PI Awareness Materials
• IDF Website, Press Release & Blog
• IDF Social Media
• PI Awareness & WPIW Video
CIS & IDF Partnership

The Clinical Immunology Society (CIS) and the Immune Deficiency Foundation (IDF) collaborated to celebrate National Primary Immunodeficiency Awareness Month in the U.S. this April and World PI Week, April 22 -29, 2016.

- To further engage the community, both organizations mailed IDF educational materials to all CIS members (more than 600) for them to share with their patients and families.
- IDF & CIS issued a joint press release about the partnership.
- During the CIS Annual Meeting, held April 14-17, 2016 in Boston, MA, IDF gave participants PI awareness t-shirts that encouraged people to “THINK ZEBRA!”
IDF Meetings & Events Across U.S.

Hosted various events throughout the U.S., which were listed on the WPIW Map of Events.

**April 2**
IDF Family Conference Day – Philadelphia, PA
IDF Get Connected Group – Portland, OR

**April 8**
IDF Nurse Advisory Committee Meeting – Baltimore, MD

**April 9**
IDF Get Connected Group — Alpharetta, GA
IDF Get Connected Group — Charlotte, NC

**April 14**
Clinical Immunology Society Meeting – Boston, MA

**April 16**
IDF Get Connected Group – San Francisco, CA
IDF Get Connected Group – St. Louis, MO

**April 19**
IDF Get Connected Group — Burke, VA

**April 20**
IDF Young Adult Webinar: Fitting Your Medical Care into a Busy Life - Online

**April 21**
IDF Advocacy Day – Washington, DC

**April 24**
IDF Get Connected Group – Frankfort, IL

**April 30**
IDF Education Meeting – Omaha, NE
IDF Get Connected Group – Lakewood, CO
IDF Family Conference Days

IDF Family Conference Days are one-day education meetings for individuals with primary immunodeficiency diseases and their family members. While parents are attending educational meetings, youth enjoy fun, age-appropriate activities and sessions.
IDF Get Connected Groups

IDF Get Connected Groups are designed to connect individuals diagnosed with primary immunodeficiency diseases and family members in their local communities.

Alpharetta, GA

San Francisco, CA

Burke, VA
The IDF Nurse Advisory Committee increases awareness of primary immunodeficiency diseases through professional education and outreach on a national and international level. Their annual meeting was held April 8, 2016 in Baltimore, MD.
IDF Advocacy Day

On Thursday, April 21, more than 75 IDF volunteers traveled to Washington, DC to advocate on behalf of those with primary immunodeficiency diseases. They represented 35 different states and attended over 160 meetings.
IDF Staff

With the help of TZ the IDF Zebra, the official IDF mascot, IDF staff helped spread awareness in Towson, MD.
SCID Screening in Maryland

During the month of April, the home state of the Immune Deficiency Foundation, Maryland, became the 37th state to begin screening newborns for Severe Combined Immune Deficiency (SCID).

As of today a total of 38 states in the U.S. now screen newborns for SCID.
National Volunteer Week

National Volunteer Week was celebrated from April 10-16. We featured many stories on the IDF blog to thank volunteers across the country.

• Lauren Dunlap: A volunteer’s view of the 2015 Charlotte Community Walk

• Larry M. Berkelhammer, PhD: Get to Know an IDF Get Connected Group Leader

• Theresa Kollman: Learn more about our volunteers during National Volunteer Week
IDF Plasma Partners Program

The IDF Plasma Partners Program creates awareness about primary immunodeficiency diseases and shows the intertwined relationship between patients, plasma donors and employees in plasma collection centers.

- **April 1**: CSL Plasma Kicks Off IDF Plasma Partners Program – THINK ZEBRA!
- **April 5**: CSL Plasma welcomes IDF volunteers
Featured World PI Week in IDF ADVOCATE newsletter
• Mailed to over 40,000 individuals

Highlighted in the monthly IDF e-Newsletter
• Sent to over 20,000 people
PI Awareness Materials

Encouraged PI community to promote awareness with IDF materials and initiatives:

Learn More – Awareness Poster & Business Card
- Available on IDF website for download or order
- Shared on Facebook, Twitter, Instagram and LinkedIn

THINK ZEBRA! Campaign
- In medical school, many doctors learn the saying, “when you hear hoof beats, think horses” 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. Patients with PI are the zebras of the medical world. So IDF says THINK ZEBRA!
IDF Website & Blog

Featured Awareness Month and WPIW on IDF website homepage and posted additional info at: www.primaryimmune.org/awareness

- Website received **130,592 sessions** in April 2016
- Issued a national press release highlighting Awareness Month and WPIW
- Created a new International Section
- Included information about how the community could get involved on the IDF Blog

*Sessions:* A session is the period time a user is actively engaged with your website, app, etc. All usage data (Screen Views, Events, Ecommerce, etc.) is associated with a session.
International Section

During World PI Week, the Immune Deficiency Foundation (IDF) debuted a new International Section on www.primaryimmune.org.

• Many IDF resources have been translated into other languages.
• IDF publications have been used as the basis for translations from other National Organizations as well.

www.primaryimmune.org/international-section
5 Simple Ways to Spread the Word

IDF e-mailed over 26,000 people in the PI community to share how they could help spread awareness in just 5 simple ways!

1. Share IDF “Learn More” Poster
2. Spread the Word on Social Media
3. Join the Global Effort with WPIW
4. Pick a Day to Wear Zebra
5. Tell Us How You’re #zebrastrong
IDF Blog Features during April

• **30 Days How CVID Has Affected My Life**
  For the month of April, young adult, Kayla Kuehl, shared how CVID affects her life every day.

• **16 Things People with PI Wish Others Understood**
  Members in the community shared things with us that they wish the general population knew about PI. We reached over 59,000 people.

• **Michigan woman shares battle with Primary Immunodeficiency for World PI Week**
  IDF Volunteer, Julie Fetch, shared her story about PI with her local TV station.

• **World PI Week: 7 Days to Raise Awareness of Primary Immunodeficiency**
  Press release and blog post to the PI community.
IDF Social Media

Graphics were used in all IDF social media profile and cover photos.
• Facebook (Both IDF and IDF Walk for PI)
• Twitter
• Instagram
• LinkedIn
IDF Facebook

IDF’s Facebook page continues to be our top social network and is increasing with new fans every day. We gained 632 new fans in the month of April, making us very close to 11,000 Facebook fans! Our total post reach for the month was 682,611 people.

Top Posts of the Month

• 16 Things People with Primary Immunodeficiency Wish Others Understood Ashanthi De Silva, IDF volunteer and The Mighty staff member shares 16 things people with PI wish others understood garnered from comments from IDF fans during World PI Week. #piawareness #worldpiweek #wpiw
  Reached 59,292 people and was shared 405 times with 1,299 reactions and 5,211 clicks.

• 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. So IDF says THINK ZEBRA! #thinkzebra #piawareness
  Reached 35,787 people and was shared 382 times with 1,103 reactions and 2,321 clicks.
Twitter - @IDFCommunity

IDF gained 96 new followers, 111 mentions, 334 retweets and 350 favorites throughout the month. Our top posts featured primary immunodeficiency facts and quotes.
Instagram - @IDFCommunity

IDF gained 54 new followers on Instagram a total of 1,057 likes and the most engaging hashtags used were #piawareness and #zebrastrong. Similar to Twitter, facts and quotes, along with zebra inspired posts, generated the most interest.
LinkedIn

LinkedIn is continuously growing, and in April IDF gained 35 new followers and had some of our top engagements while bringing awareness to PI and WPIW.

Top Post of the Month

This means that in the U.S., approximately 1 in 1,200 persons have a diagnosed PI. Share to help get the word out about primary immunodeficiencies.
Zebras of the PI Community

Many people from the PI community sent IDF photos of their zebras and little zebras, and we shared them through various social media platforms. Here are a few examples:
Zebras of the PI Community
Zebras of the PI Community
THINK ZEBRA! Celebration in Iran

The Immunology, Asthma and Allergy Research Institute celebrated World PI Week in Iran with a cheerful "Patient-Healthcare Providers" gathering inspired by THINK ZEBRA! IDF featured the celebration on our blog.
PI Awareness Month & WPIW Video

After such a wonderful response from the community throughout PI Awareness Month and World PI Week, IDF posted this video thank you message from Marcia Boyle, IDF President & Founder, and TZ the IDF Zebra.
We’re looking forward to promoting even more awareness of PI in 2017!