Joining Together to Create Awareness

CIS and IDF Celebrate National Primary Immunodeficiency Awareness Month and World PI Week

Wearing bright blue t-shirts that urged everyone to THINK ZEBRA!, members of the Clinical Immunology Society (CIS) and the Immune Deficiency Foundation (IDF) joined forces to celebrate National Primary Immunodeficiency Awareness Month and World PI Week at the CIS Annual Meeting in April.

At the meeting, renowned immunologists presented new research findings and discussed treatments for primary immunodeficiency diseases (PI) with more than 600 attendees. Throughout the conference, IDF distributed the Foundation’s materials and resources. To show solidarity among those caring for and working on behalf of the PI community, IDF distributed PI Awareness t-shirts to all CIS Annual Meeting attendees, encouraging them to spread the word.

“The Clinical Immunology Society is devoted to fostering developments in the science and practice of clinical immunology to promote excellence in patient care. There have been many strides made in the treatment and care of patients with primary immunodeficiencies, and it is critical for patients to receive proper treatment under the care of a specialist,” said Jordan Orange, MD, PhD, President of CIS.

“We are pleased to partner with IDF during Awareness Month and World PI Week to help increase understanding of these complex diseases on a national and international level.”

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Joining Together to Create Awareness

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Every day advocates at IDF hear from individuals with PI wanting to learn more. We know that when someone is diagnosed, they are searching for information. IDF has a wealth of resources, groundbreaking education and information from a legion of dedicated professionals, many who are members of CIS, to help meet this need.

However, a hurdle IDF faces is getting resources into the hands of those who need them the most—people living with PI. To engage this community, CIS and IDF jointly mailed IDF educational materials to all CIS members for them to share with their patients and families.

“IDF is committed to raising awareness to help lead to early diagnosis and appropriate treatment for people with PI,” said Marcia Boyle, IDF President & Founder. “We are dedicated to ensuring those diagnosed have the information and resources they need. This partnership with CIS strengthens the outreach to the PI community.”

The partnership continues as the organizations collaborate to conduct a survey of immunologists. IDF and the Advocacy Committee of CIS would like to know more about how the current payor (health insurance) environment affects an immunologist’s ability to diagnose and treat patients with PI. We hope to find out how much time and effort is spent with pre-authorizations and denials, and what steps they need to take for approval of Ig therapy and other treatments. The survey also will look at the frequency and magnitude of all these issues as well as specific insurance policies and procedures that may interfere with the appropriate, timely treatment of patients with PI. We intend to use the data collected to better advocate for patients from pre-diagnosis through treatment.

IDF looks forward to working with CIS and its members in the future to continue to promote awareness of PI and provide accurate information for those living with PI and seeking answers.

To see other IDF activities for National Primary Immunodeficiency Awareness Month and World PI Week, go to www.primaryimmune.org/awareness.

New International Section of IDF Website

During World PI Week 2016, IDF debuted a new International Section on www.primaryimmune.org. This section showcases the many IDF resources that have been translated into other languages, as well as IDF publications that have been used as the basis for translations from other patient organizations around the world.

www.primaryimmune.org/international-section

THINKing ZEBRA throughout April

When members of the PI community gathered during Awareness Month and World PI Week, they encouraged everyone to THINK ZEBRA! by proudly wearing their awareness t-shirts.

IDF Get Connected Groups

IDF Nurse Advisory Committee Meeting

IDF Advocacy Day

Thank you to those who helped promote PI awareness across the country! Would you like to share how you created awareness? Send your story and photos to us: info@primaryimmune.org.
Groundbreaking New Research on CVID Published in The New England Journal of Medicine

The New England Journal of Medicine recently published, “Loss of B Cells in Patients with Heterozygous Mutations in IKAROS,” an article detailing groundbreaking new research about Common Variable Immune Deficiency (CVID). In this study, funded by the National Institutes of Health (NIH) among other institutions, researchers pinpointed the genetic mutation responsible for an inherited subtype of CVID. Although not changing the current treatment of the disorder, identifying the gene can indicate potential complications and outcomes. In addition, the publication of the study findings in such a renowned journal helps increase awareness of primary immunodeficiency diseases among the medical community.

How the Collaborative Project Began

The spark for this research project was ignited at the 2014 Clinical Immunology Society Summer School. At this educational event, allergy and immunology fellows take part in an intensive three-day course focused on primary immunodeficiency and immune dysregulation diseases lead by expert faculty. Lead author Dr. Rosenzweig explains, “While discussing with Dr. Cunningham-Rundles (Mt. Sinai Medical Center) about candidate genes (genes that might cause and explain a disease) for CVID, we realized that both of us had detected families diagnosed as CVID and carrying mutations in IKAROS. This fortuitous coincidence initially brought Dr. Conley (Rockefeller University) to the nascent research group and soon after, Dr. Hill (University of Utah Health Care) and Dr. Orange (Texas Children’s Hospital), who have also diagnosed CVID patients with IKAROS mutations at their centers. Investigators working with Dr. Conley at Rockefeller University and our team at the NIH conducted the experiments to determine the role of IKAROS mutations in CVID.”

What Researchers Discovered

Researchers found that patients with mutations in IKAROS have a progressive loss of B cells and immunoglobulins underlying their immunodeficiency. The disease is inherited in a dominant way: having one IKAROS gene mutated (out of the two we all carry) is enough to have the disease. A patient with an IKAROS mutation has a 50/50 chance to transmit the disease to their children. However, even though these mutations are present at birth, manifestations are not always apparent early in life. Some patients with IKAROS mutations can be asymptomatic for many years before they develop indications of CVID, while others can present with symptoms during infancy.

In terms of the signs of the disease, infections (pneumococcal in particular) were the most common ones, but a distinctive type of pediatric leukemia (B cell acute lymphoblastic leukemia) and some forms of autoimmunity (e.g., immune thrombocytopenia, ITP) were also seen. As for treatment and outcome, patients with mutations in IKAROS presenting only with infections had a relatively benign course of disease, even if the prophylactic treatment they were getting (Ig replacement therapy and antibiotics) was not always optimal.

What This Means for the Future

Mutations in IKAROS will likely explain several CVID cases in the future, but only time will tell which percentage of CVID patients has IKAROS deficiency. In the authors’ experience and after they diagnosed 29 cases in 6 families, another 132 CVID patients were tested and no further cases were confirmed. CVID patients with a family history of immunodeficiency, low or absent B cells and elevated CD8+ T cells are the ones more likely to carry mutations in IKAROS. A distinctive aspect

New IDF Research Grant Program

IDF is pleased to announce a new seed grant program to encourage and support Patient Oriented Research on Primary Immunodeficiency Diseases. This initiative will award grants that will support well-defined research projects that have a specified benefit for improving the treatment, health, disease management or diagnosis of persons with PI. Consideration will also be given to studies that contribute to the body of medical knowledge in PI.

The program is open to applicants currently based in the U.S. and will consist of one-year grants. Award values up to $25,000, and a somewhat higher level of support is available for a few exceptional proposals. Grants are considered twice per year. Submission deadlines are July 31, 2016 and January 31, 2017.

For complete details, go to: www.primaryimmune.org/idf-research-grant-program.
of patients born with \textit{IKAROS} mutations is that the disease is progressive. “In some of the patients we studied we were able to document how their immune systems were normal at early ages and how they progressively lost their B cells, immunoglobulins and antibody function,” says Dr. Rosenzweig. “We also showed that patients with \textit{IKAROS} mutations can present with ‘full blown’ CVID, while others can have just IgA deficiency or even be asymptomatic for decades. All these findings suggest that other factors besides the \textit{IKAROS} mutation can also regulate the manifestations of the disease, even in patients within the same family.”

As genetic testing becomes more easily accessible, more patients with CVID will be found to carry mutations in already known (and yet to be described) disease-causing genes. Patients should discuss directly with their primary care teams about their best available options regarding genetic testing for their diseases. Dr. Rosenzweig says, “This new knowledge does not only imply that we can now determine the precise genetic cause in some patients with CVID, but it also gives us the opportunity to counsel them on how their disease can be genetically transmitted, provides us with potential ‘molecular targets’ we can use to more precisely treat their disease, and gives a hint on what we should be looking for in terms of complications and outcomes. On the other hand, finding the genetic cause for CVID will not necessarily imply a change of treatment.” He explains that many times treatments, such as Ig replacement therapy and prophylactic antibiotics, will remain completely the same.

The conclusions of the researchers’ work were published in \textit{The New England Journal of Medicine} (\textit{N Engl J Med} 2016;374:1032-43), one of the most prestigious medical journals in the world. According to Dr. Rosenzweig, “And this is not a trivial issue, it means that the medical community is interested and cares about primary immunodeficiencies and CVID. Patients with CVID should know that they have great teams to support their backs!”

To read the journal article, go to: \texttt{www.primaryimmune.org/ikaros}.

\textbf{Sergio Rosenzweig, M.D., Ph.D., is the Deputy Chief of the Immunology Service, Department of Laboratory Medicine Clinical Center, National Institutes of Health (NIH) and Director of the Primary Immunodeficiency Clinic at the NIAID, NIH. As a senior author of this journal article, he would like to thank all primary immune deficient patients in general and those who participated in the study in particular for their trust, patience and contributions. Without their collaboration as truly equal partners in these research projects, none of the advances that are being achieved collaboratively could be possible. Also, to the teams at the Primary Immunodeficiency Clinic at NIH, Bethesda; the Icahn School of Medicine at Mount Sinai, New York; the Children’s Research Center, Zurich; the Oslo University Hospital, Oslo; the National Jewish Health, Denver; the University of Utah and ARUP, Utah; and the Medical College of Georgia, Georgia, Dr. Rosenzweig is grateful for the effort, commitment and dedication they put both into the care and the research of patients with primary immunodeficiencies, as well as those who participated in this study.}

\textbf{NEW IDF ePubs}

You can now have access to IDF publications almost instantaneously—anytime, anyplace with your eReader. No more lugging heavy books, taking up precious storage space or searching for that misplaced book!

It’s easy. Download \textbf{IDF ePubs} today by visiting \texttt{www.primaryimmune.org/idf-publications}. Select “eBook” or “Kindle” from the drop down menu, and add it to your cart. After registering, you can download the file at no cost to you.

\texttt{www.primaryimmune.org/idf-publications}
How Does Your Quality of Life Measure Up?

Participating in Quality of Life Surveys
Most people care about their quality of life, but how do you evaluate your own?

Quality of Life (QoL) surveys assess an individual’s ability to perform routine physical and social activities and compares the individual’s score to the average scores of the larger U.S. population. This can provide useful comparisons to measure your health against others.

The information from QoL surveys, known as “Patient Reported Outcomes,” come directly from the patients’ responses without any interpretation by a healthcare provider, or anyone else.

IDF Offers PROMIS-29 Quality of Life Survey for IDF ePHR Members
IDF ePHR, the electronic personal health record for the PI community, will host the PROMIS-29 surveys every 6 months, with the next survey starting in October 2016.

PROMIS, which stands for Patient-Reported Outcomes Measurement Information System, was developed to support NIH-funded research. PROMIS measures are standardized to assess patient-reported outcomes, such as pain, fatigue, emotional distress, physical functioning and social role participation, based on common metrics allowing for comparisons among chronic conditions as well as the general population. 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.

IDF has upgraded the survey from the first round, so now it provides participants with instant customized reports of how their health compares to the general population. This information can be used as a way to better manage your health and help healthcare providers better guide your care.

To participate in future PROMIS-29 surveys, be sure to create an IDF ePHR account at www.IDFePHR.org, and you will be notified when the next survey opens in October.

If you have any questions, contact IDF at 800-296-4433 or info@idfephr.org.

IDF ePHR is exclusively sponsored by CSL Behring.

Traducción Española Ya Está Disponible
IDF ePHR - Spanish Translation Now Available

IDF ePHR, the electronic personal health record developed for patients with PI, is now available in Spanish. IDF ePHR allows you to store, track and share your health information. You can access your account from your computer, or download the app to access your information anywhere with your smartphone or tablet.

www.idfephr.org
Why Do You Walk for PI?

Since 2013, hundreds throughout the country have participated in IDF Walk for Primary Immunodeficiency and helped raised over $2 million for IDF. Whether they lace up their sneakers and walk or simply write a check to contribute, people support the walks for a variety of reasons.

We asked three walkers from 2015, “Why Do You Walk?”

Michelle Rose
*Diagnosed with Common Variable Immune Deficiency in 2014*

I volunteer and walk in hopes to raise more awareness for PI. There are many patients walking around who are sick and undiagnosed. If we can reach even a few of those individuals, they will be educated about PI and could encourage their physicians to test them for PI. I have been sick since birth myself and went undiagnosed for 40 years, even while working in the medical field. It was not until I started working for an allergist / immunologist that he noticed how often I would come into work ill and decided to test me. I walk in hopes to spread awareness and raise money for research of PI. I believe that there is power in numbers. Every little bit helps in the fight against PI.

Sam Long
*Diagnosed with Common Variable Immune Deficiency in 2004*

There are many reasons why I walk for PI with IDF. For starters, I walk to be able to give back to IDF for all they have done for me and my family over the years. Their constant support has made my journey with PI more manageable. As a member of the IDF Teen Council, I pride myself in being able to travel and speak on behalf of IDF, to explain PI to those who may not understand, and to let others know what they can do to help our community. When I was growing up, my family and I really had no idea what my disease was or where to turn for help. With the support of IDF, we are able to help families and kids so they never have to feel lost or alone like I did. Paving the way for generations to come motivates me to walk and raise funds for the fight against PI.

Carolina Rubiano
*Mom, 6-year-old son Diagnosed with X-linked Agammaglobulinemia in 2011*

My family and I walk because we are part of the PI community. We want to show our support to the IDF mission. We know that IDF is doing a lot to help PI patients. By walking, we stay active while supporting this community. Our motivation stems from our knowledge that IDF has always and will continue to improve the quality of life of PI patients. Deep in our hearts, we hope that a permanent cure to our son’s PI condition will be discovered soon.

Register for IDF Walk for PI at: www.walkforPI.org.

Why do you walk for PI? IDF wants to get to know our participants and learn more about how the walks have made a difference in their lives. To share your story, email walk@primaryimmune.org.
Walking together, we can make a difference in the lives of those affected by PI. Across the country, members of the PI community are bringing people they know together in the fight against PI, and we want you to be a part of it.

By joining thousands of individuals in IDF Walk for PI 2016, you can help create a better future for generations to come by funding vital programs and resources, powering research, and spreading awareness of PI. Will you join us?

National Walk Sites

Cleveland - Wade Oval - September 25
Boston - Boston Common - October 2
Minneapolis - Minnehaha Park - October 2
St. Louis - Queeny Park - October 9
Philadelphia - Penn’s Landing - October 16
Chicago - Cantigny Park - October 23
New York City - Foley Square - October 23
Atlanta - Brook Run Park - October 29
Charlotte - Symphony Park - November 5
Los Angeles - Tongva Park - November 6
Houston - Discovery Green - November 13
Fort Lauderdale - North Hollywood Beach Park - November 20

Don’t live near any of the 12 National Walk sites?
Launch your own Community Walk or create a team as part of our National Virtual Walk.

2016 Community Walk Sites
Blountville, TN - Sullivan Central HS - September 17
Omaha, NE - Miller’s Landing - September 18

2016 National Presenting Walk Sponsor:
Shire

2016 National Walk Sponsors:
Coram CVS Specialty Infusion Services
CSL Behring
Grifols
Horizon Pharma
IgG America | ASD Healthcare | US Bioservices
Kedrion Biopharma
Octapharma
Option Care

Let’s bring together the entire PI community—every individual, family, and friend!
For more information, go to www.walkforPI.org.
Parenting a Child with a Chronic Illness

By Maryland Pao, MD
Clinical Director, National Institutes of Mental Health

Parenting has never been easy, but parenting today has additional challenges in a globally connected, fast-paced, information- and opinion-saturated world. Everyone has something to say about how to parent healthy kids, but what about when you have a child with a chronic medical condition? It’s hard enough to try to help your child roll with the punches everyday life hands you. It’s even harder when your child has to take medicines, go to the doctor or hospital frequently, disrupting life with school and friends. It’s really hard when you’re worried about your child’s future.

I have talked with hundreds of parents of chronically ill children to glean what helps some: many talk about the importance of keeping their child on as typical a developmental path as they can. Helping a child reach for normative developmental milestones such as increasing independence, building a strong self-identity and developing intimate relationships as the child matures can foster a sense of competence and confidence. There is an obvious tension in trying to walk this fine line, between pushing your child towards reaching these goals while at the same time acknowledging that some may be hard to attain in the context of physical illness.

A child’s ability to adjust to an illness is not directly related to the severity of the illness; many other factors determine coping and adaptation. Here are a few things I’ve observed:

Your child has X; X does not define your child or you. In reality, we all have traits or experiences that make us different from one another, but we all share things that make us human such as a sense of humor, an ability to share or a need to be loved. Having a disorder does not take away the things that make us human or determine our personality. It is important not to let a diagnosis become one’s identity.

While you’re tending to critical medical needs, don’t forget social and psychological needs-these will be important when your child is well. We are an accumulation of all our experiences including ones we can barely even remember. While we must focus on life-threatening aspects of care at times, we should be mindful that social skills and psychological development are important to attend to as well. If these are ignored, these areas often become significant problems when your child is expected to resume “normal” life.

Acknowledge your grief and losses. No one expects to have a sick child. Parents think about seeing Tommy playing soccer or Sarah swimming competitively. They think about college, job, marriage and grandparenthood, not hospitals, intensive care units, pain and even death. Give yourself permission, at times, to mourn the loss of what might have been without feeling guilty. But if you dwell too long on the “what ifs,” it might be helpful to talk with others or even seek professional help.

Avoid the “Prince/Princess” Syndrome. Parents of sick children have to walk a fine line when it comes to discipline. The truth is children need structure and limits even though they are always trying to push the limits. That is the point. They need something to push against. Parents feel sorry for their sick children and limits start to go out the window, especially in the hospital. You should expect appropriate behavior from your child such as being cooperative, not being rude, and doing school work and chores even in moments when your child is not feeling totally well. You should expect your child to do things even when he or she doesn’t want to. This is hard to do consistently, even for hospital staff.

Have expectations of your child at each developmental stage. Remember to focus on life skills like reading a bus schedule, planning to cook a meal, or doing laundry, not just academics. Help your child figure out their strengths and gain mastery. Being good at playing music or writing poetry or computer coding may lead to increased self-esteem. This does not include being good at watching TV or playing video games. This does include preparing to “let your child go” as they get older. Periodically review with them their medical condition and medications as they age and their understanding grows; clarify and learn what they actually know, and want or don’t want in their treatment.

“Apples don’t fall far from trees.” Take time for yourself to examine your own strengths and foibles, and consider how they might be contributing to how you are handling stress and uncertainty. Is your child avoiding dealing with problems? Do
you do that? Be conscious of the way you want to raise them the same or differently from the way you were raised.

**Remember siblings and significant others have needs too.**
Having a sick child can be very consuming but make time where you give your undivided attention to your spouse, significant other or your other children. Regular family sit down meals, even just weekly, are a good place to let everyone have a turn to speak and share.

**Enjoy your child.** Every child, sick or healthy, is special, so find three things to be grateful for at the end of each day. Positive thinking won’t change the diagnosis, but it can help how you cope and give you hope.

Use or find social supports. In the best of circumstances, parenting is hard work, so do not be afraid to ask for guidance. You can’t do it all. Research consistently finds that those who can ask for and receive help have better overall health and psychosocial outcomes. Family, community, organized religious groups, and advocacy organizations are just a few of the available resources. Within many medical communities, child life, social workers, psychologists and child/adult psychiatrists are available to assist parents.

Depression and anxiety are important to identify proactively because there is something that can be done to help. This is important both for your child as well as for you, a parent. If you find that you are feeling sad, down, or if you are not finding pleasure in things that typically make you happy more of the day than not over a period of a couple of weeks, or if you are having ongoing trouble with poor sleep and appetite, talk to your physician. It’s critically important that as parents you take care of yourselves. This will naturally benefit all of those with whom you come into contact with, most importantly your children.

Through all my conversations, these are some of the key lessons that have emerged. I've seen that despite having a sick child, parents need to provide structure, discipline, and consequences for misbehavior to help your child develop as much independence, confidence and maturity as possible. Who knows what curative treatments are around the corner, and you want your child to be ready emotionally when they are.

**Dr. Pao is the Clinical Director of the National Institute of Mental Health Intramural Research Program at the National Institutes of Health. Dr. Pao is also the Deputy Scientific Director. She serves as Chief of the Psychiatry Consultation Liaison Service in the Hatfield Clinical Research Center.**

Some of the content of this article was presented at the IDF 2015 National Conference in New Orleans, LA on June 26, 2015. To view recordings from the conference, go to [www.primaryimmune.org/idf-videos](http://www.primaryimmune.org/idf-videos).

This article does not necessarily reflect the views of the NIMH, NIH, HHS, or the U.S. Federal Government.

**References:**

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**For Our Youngest Members of the PI Community**

IDF always keeps the youngest members of the PI community in mind when developing programs and resources. Youth Programs are offered at every IDF National Conference, Retreat and Family Conference Day. While parents are attending educational sessions, their children benefit from kid-friendly activities, helping them understand PI and connecting them with others going through similar circumstances.

IDF publications offer valuable information for both children and parents. The *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases* includes chapters devoted to each life stage, complete with advice for parents of children with PI, on how to help them understand their disease, normalize their life and coordinate their healthcare. *Our Immune System* children’s storybook educates children through characters that explain how the immune system works. And, *A Zebra Tale*, a charming illustrated storybook written for children and their families, provides hope and encouragement.

The IDF Arcade, featured on [www.primaryimmune.org](http://www.primaryimmune.org), contains games inspired by the characters from *Our Immune System*. One of the most popular games Whack-A-Germ, gives players the satisfaction of whacking the germ while watching out for friendly T-cells and phagocytes. The Whack-A-Germ app can easily be downloaded to your smartphone or tablet. It is available free from Google play (Android) and the iTunes store (iOS). Search for “IDF Game.”

For more information about the IDF Youth Programs, publications and Whack-A-Germ app, go to [www.primaryimmune.org](http://www.primaryimmune.org).

**The IDF Arcade was made possible by an unrestricted educational grant from IgG America, ASD Healthcare, and US Bioservices.**
Donor Spotlight: Lisa and Jim Betsworth

“Contributing towards IDF’s efforts helps us pay it forward”

My husband is a pharmacist, and I am a nurse, married for almost 38 years. Our youngest daughter, Diana, was diagnosed with Common Variable Immune Deficiency (CVID) at age 26 after being sick for over 10 years. After her diagnosis, we knew we needed more information. The physicians treating her were initially unaware of the most recent treatment options, so we turned to IDF for help.

The complicated health care system is difficult to navigate, and when you have a rare disease, it’s that much harder. Our family sought out many “experts” for 10 years before our daughter was finally diagnosed – if only she was tested for PI earlier, she would have been spared much illness and suffering. Thankfully, today she is a mom of two young boys, works as a physical therapist and has an excellent team of doctors in place for her PI.

We are so inspired and thankful for what IDF does – IDF means the world to us! We knew we wanted our support to be ongoing for us – our hope is that by giving monthly, it will collectively make a difference. Knowing that we are contributing towards IDF’s efforts helps us “pay it forward” for all they have done for my daughter and for our family.

Thank you to Lisa and Jim for your monthly donations and for sharing why you give to IDF! Join the Betsworths and become a monthly donor today. Call 800-296-4433 or email development@primaryimmune.org.

IDF Advocacy Day 2016
Fighting for the PI Community on Capitol Hill

Over 75 members of the PI community participated in IDF Advocacy Day 2016 on Thursday, April 21. The inspiring group made their way to Capitol Hill in Washington, DC to advocate on behalf of those with PI and encourage their legislators to oppose CMS proposed Medicare Part B Drug Payment Model, which could potentially put lifesaving medications such as immunoglobulin therapy (Ig) out of reach for some patients.

IDF Advocacy Day, April 21, 2016, Washington, DC

Advocates from across the U.S., representing more than 35 states and ranging in age from 15-75, all with diverse backgrounds, joined IDF in this effort. These dedicated advocates attended over 160 meetings with members of Congress and their staff, putting a face to the cause and emphasizing the unique healthcare needs of the PI community.

Stay tuned for IDF posts on Facebook (www.facebook.com/ImmuneDeficiencyFoundation) and Twitter (@IDFCommunity) as well as IDF Action Alerts to help stop the Medicare Part B Drug Payment Model from moving forward. To learn more about this proposed model, visit www.primaryimmune.org/idf-advocacy-center.

Sign up for IDF Action Alerts to stay informed and involved, go to: www.primaryimmune.org/action-alerts.

Lisa and Jim Betsworth with their family. From left, Mike Castro (son-in-law), Sarah Castro (eldest daughter) holding Mara Castro (age 3 granddaughter), Helo Castro (age 5 grandson), Lisa and Jim', Diana Hettenbaugh (youngest daughter) holding Graham (age 15 months grandson), Zach Hettenbaugh (son-in-law) and Mason Hettenbaugh (age 3 grandson).
**IDF Legacy Society**

The IDF Legacy Society recognizes those who have included the Immune Deficiency Foundation (IDF) in their wills or who have created other types of planned/legacy gifts in support of IDF. If you have chosen to include IDF in your financial or estate plans, please contact John G. Boyle, Vice President of Development, at jboyle@primaryimmune.org to learn more about becoming a member of the IDF Legacy Society.

**Holli Jo Bess**
**Richard Beverly**
**Varun Bhaskaran**
**Kathleen Bone**
**Daniel “DJ” Burdzinski**
**Bud Calkins**
**Lisa Codispoti**
**Lillian Davidson**
**Delores Goldsmith**
**Kasey Goodwin**
**Ruth Green**
**Abha Gupta**
**Brad Kirkendall**
**Mary Ann Knutson**
**Michael Kornweiser**
**Jennifer Lipschultz**
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**Richard Schwartz**
**James “Jimmy” Seymour, Jr.**
**Scott Solberg**
**Jon Westmoreland**
**Ireta Williams**
**Helen Woodall**

**WITH GRATITUDE MEMORIAL GIFTS**
**February 2, 2016 – May 25, 2016**

**El Cuento de Una Cebra**

The popular illustrated storybook, *A Zebra Tale from the Immune Deficiency Foundation*, is now available in Spanish. The story was written for children—or the young at heart—living with PI and their families to provide hope and encouragement.

*El Cuento de Una Cebra* chronicles the journey of a young horse who faces recurrent infections, struggles to understand why he gets sick often, and ultimately finds contentment and acceptance when he is diagnosed with a PI, discovering that he is a zebra.

Individuals and families can download or order a hard copy of *El Cuento de Una Cebra* at: www.primaryimmune.org/idf-publications.

*El Cuento de Una Cebra*’s translation and printing was made possible by Grifols. The development of this publication was made possible by the American Legion Child Welfare Foundation.

Los individuos y las familias pueden descargar o solicitar una copia impresa de *El Cuento de Una Cebra* en: www.primaryimmune.org/idf-publications.

**IDF Common Ground App Launched**

Teens living with PI now have an app to connect with other teens. The new IDF Common Ground app provides access to IDF Common Ground, IDF’s social network exclusively for teens, ages 12-18, living with PI, in an easy and more convenient way.

Teens can:
- Discuss topics important to them as they deal with PI
- Share status updates to the News Feed
- Upload photos to share with others
- Find new friends in the PI community

Download the app for free!

Questions? Email us at idfcommonground@primaryimmune.org.

www.idfcommonground.org

*IDF Common Ground is sponsored by CSL Behring, IgG America/ASD Healthcare/US Bioservices and Shire.*