IDF 2015 National Conference in New Orleans

The primary immunodeficiency community gathered in New Orleans for the Immune Deficiency Foundation (IDF) 2015 National Conference, June 25-27, and the Crescent City served as the perfect setting for the high energy and enthusiasm of more than 1,360 attendees. The conference—the 8th in the Foundation’s 35-year history—gave individuals and family members the opportunity to learn from experts in the field and to meet with others who understand what it’s like to live with primary immunodeficiency (PI). The IDF National Conference is the only national meeting in the U.S. specifically for individuals and families living with PI, and for many attending can be life-changing. As one conference participant commented, “Thank you for providing this opportunity for all of us to come together. It truly was life-changing for my family and myself.”

The three days included more than 40 presentations from world-renowned healthcare and life management experts covering various topics, including advancements in diagnosis and treatments, allergies, antibiotic and antifungal therapies, autoimmunity, complementary and alternative medicine, nutrition, mental health, school, employment, health insurance and more. “Every presenter was more than willing to share time and information after presentations and throughout the conference,” said one attendee. “Very professional, polite, and knowledgeable on their area of expertise.”

White House Honors IDF’s Marcia Boyle as a “Champion of Change” for Precision Medicine

On July 8, 2015, Marcia Boyle, IDF President & Founder, was one of nine individuals recognized by the White House as “Champions of Change” for Precision Medicine, which honors the work being done by patients, researchers, innovators, and advocates who are advancing our understanding of health and disease by harnessing data to account for individual differences in people’s genes, environments, and lifestyles to improve patients’ health.

The President’s Precision Medicine Initiative was launched earlier this year to enable a new era of medicine through research and technology that empowers patients, researchers, and providers to work together toward development of individualized treatments. Marcia was chosen as a “Champion of Change” for her work at IDF, specifically IDF ePHR, the electronic personal health record for the primary immunodeficiency (PI) community, and PI CONNECT, the IDF Patient-Powered Research Network.
The IDF 2015 National Conference brought together attendees from 39 states and around the world, including Australia, Belgium, Canada, England, Germany, Israel, Italy, Slovenia, South Korea, Switzerland, and United Arab Emirates. The IDF Exhibit Hall featured services and products for the PI community. The IDF Youth Program provided children, tweens and teens with fun, age-appropriate educational activities.

The conference was bursting with sessions and events. Some highlights of note included:

**Welcome Reception**

The Welcome Reception began with the first official welcome and ended with a second line parade through the streets of New Orleans. And along the way our zebra got a name! TZ the IDF Zebra, named to remind everyone to THINK ZEBRA!, finally has its own moniker and celebrated by dancing in the streets with hundreds of other conference attendees as they waved their zebra handkerchiefs! Welcome Reception sponsored by Baxalta US Inc.

**Opening Session**

The Opening Session featured patient-powered research. Marcia Boyle, IDF President & Founder, along with Kathleen Sullivan, MD, PhD of The Children’s Hospital of Philadelphia, PI CONNECT Principal Investigator, and Joe V. Selby, MD, MPH, Executive Director of Patient-Centered Outcomes Research Institute (PCORI), shared how individuals with PI are the new power behind research with IDF ePHR and PI CONNECT. Read more on page 8. Opening Session sponsored by Baxalta US Inc.

**Breakfast Symposia**

The Breakfast Symposia focused on interests and needs of the PI community. Friday morning’s symposium, “PI: New Discoveries & Future Treatments” addressed new breakthroughs and innovations in the field of PI and provided insight into the future management of PI. Saturday’s breakfast took a different turn, and “Knocking Down the Barriers to Care” presented information on changes with health insurance and policy initiatives. These issues directly affect the PI community and practical issues were targeted. Friday Symposium sponsored by Baxalta US Inc. Saturday Symposium sponsored by CSL Behring.

**Special Symposia**

For the first-time, IDF hosted a Special CGD Symposium for those living with Chronic Granulomatous Disease (CGD) to learn more about treatment, news and research specific to this disease. Over 75 patients and family members attended this exceptional meeting presented by top medical experts, while also having the opportunity to discover so much from each other. Find information about CGD at www.livingwithCGD.org. With support from The WAS Foundation, IDF hosted a special symposium on Wiskott-Aldrich Syndrome (WAS). Healthcare professionals presented the latest information regarding diagnosis and treatment of WAS. CGD Symposium sponsored by Horizon Pharma.

**IDF Zebra Gala**

Many wore their best zebra-inspired outfit and donned a mask at the IDF Zebra Gala festive celebration. Many generous attendees contributed to the THINK ZEBRA! Silent Auction, and everyone paid tribute to deserving award recipients as they were honored during the awards program. See page 4 for more about the award recipients. IDF Zebra Gala sponsored by CSL Behring.
IDF Night at Mardi Gras World

IDF Family Night began with a tour of the fascinating Mardi Gras World, the float-building warehouse complete with amazing parade floats and unique characters. They enjoyed New Orleans style buffet at the indoor replica of an antebellum mansion and danced to the music of a rousing zydeco band.

The IDF 2015 National Conference brought together a remarkable community that grows stronger each year. With the latest information and research from experts in their fields along with vital tools and resources, it is a crash course for individuals and family members on how to manage living with PI and advocate for themselves. One attendee remarked, “I learned more in 1 day than I have in 11 years!”

Introducing TZ the IDF Zebra

With a big grin and bold stripes, the IDF zebra has become a celebrity in our community and now has an official name: TZ the IDF Zebra! TZ stands for THINK ZEBRA! Many physicians are taught, when you hear hoofbeats, think horses, not zebras, and focus on the likeliest possibilities to make a diagnosis. However, physicians need to look for the unusual to detect patients with primary immunodeficiency. So IDF says THINK ZEBRA!

Follow TZ on Instagram and Twitter @TZtheIDFZebra

Thank you IDF 2015 National Conference Sponsors!

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SAVE THE DATE

IDF 2017 National Conference
Anaheim, CA
June 15-17, 2017
Outstanding Work and Dedication to PI Community Recognized

At the IDF 2015 National Conference, the Immune Deficiency Foundation (IDF) had the opportunity to honor those who have done outstanding work on behalf of the primary immunodeficiency (PI) community. This year, we expanded our honors with the addition of three new awards. We carried on the tradition of honoring a member of the medical or scientific community with The Boyle Scientific Achievement Award.

The Boyle Scientific Achievement Award
Established by IDF in 1992, The Boyle Scientific Achievement Award has paid tribute to a member of the medical or scientific community, selected by the IDF Medical Advisory Committee, who has extensively contributed toward improving the diagnosis and care of patients with PI. The 2015 recipient is William T. Shearer, MD, PhD, Professor of Pediatrics and Immunology at Baylor College of Medicine and Former Chief of the Allergy and Immunology Service at Texas Children’s Hospital. Dr. Shearer directs the David Center at Texas Children’s Hospital, established in 1984 and named after David Vetter, affectionately known as the boy in the bubble, who had Severe Combined Immune Deficiency (SCID). Dr. Shearer cared for David and for this he holds a special place in the PI community. He has been active in and served in leadership roles for professional and clinical immunology organizations at the national level for many years. He is a longtime member of the IDF Medical Advisory Committee and has been a contributor to IDF publications. Dr. Shearer’s research has produced 354 peer-reviewed publications, 81 book chapters, and has made 266 presentations at national and international meetings. His dedication to the treatment and care of individuals diagnosed with PI is exceptional, and the IDF community is indebted to Dr. Shearer for his extraordinary work.

IDF Visionary Leadership Award
IDF has been incredibly impactful through the years because of the efforts of many people who believe in the Foundation’s mission. In honor of our 35th Anniversary, an award was created to recognize two exceptional people who have volunteered their efforts since the beginning.

Rebecca Buckley, MD, the J. Buren Sidbury Professor of Pediatrics and Professor of Immunology at Duke University Medical Center, is an internationally renowned leader in research and treatment of PI. She has been a pioneer in the use of non-ablative bone marrow transplantation to provide immune reconstitution to infants with SCID, and a passionate proponent for newborn screening for SCID. Dr. Buckley has been an author or co-author on more than 300 scientific publications, and has received many of the top awards in medicine, including election to the National Academy of Medicine.

IDF Impact Award
The IDF Impact Award, another new honor this year, recognizes many years of commitment and contributions to IDF. The recipient, the American Legion Child Welfare Foundation, not only helped IDF get its start, but it has also continued to support IDF’s efforts to educate children throughout the years. After an initial grant to create the first IDF newsletter and materials, subsequent grants from the Foundation enabled us to produce our first children’s book, Our Immune System, and the first edition of the IDF School Guide. Most recently, the Foundation supported our new children’s storybook, A Zebra Tale from the Immune Deficiency Foundation. The grants IDF has received from the Foundation were absolutely essential in the formation of IDF, and their continued support has helped create some of our most popular educational resources. Mr. Herbert Petit, Jr., a member of the Foundation’s Board of Directors, accepted the award.
Sciences. She was the 4th recipient of the IDF Boyle Scientific Achievement Award. In 1981, Dr. Buckley served in the first group of physicians to be part of the IDF Medical Advisory Committee, and she remains on the MAC to this day, serving as Chair since 2003. She has authored and reviewed countless IDF medical publications and articles. Nominated by IDF, she served on the HHS Secretary’s Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, playing a pivotal role for the addition of SCID onto the national newborn screening panel. Dr. Buckley has presented at countless IDF medical meetings and conferences, and she has been a constant and dependable resource for IDF. IDF is grateful for Dr. Buckley’s 35 years of service, and, most importantly, for being a remarkable physician ultimately devoted to the well-being of patients and families.

**IDF Visionary Leadership Award**

**John M. Boyle, PhD** helped found IDF and has been a driving force behind the Foundation for 35 years. After his son was diagnosed with PI, he and wife Marcia, discovered that patient education information was almost non-existent and families’ needs were not being met. Along with another family and their son’s immunologist, John and Marcia decided to create a national patient organization for PI, formally incorporating IDF in 1980. John has a PhD in Political Science, and has developed international recognition in public opinion (survey) research, which has been his profession. Since the beginning, John has been a dedicated member of the IDF Board of Trustees, bringing a strategic perspective to board deliberations, encouraging IDF to examine data and explore new technologies. In 1992, John co-wrote, with Jerry Winkelstein, MD, the proposal to the NIH for the CGD Registry, the first registry for PI in the world at the time, later becoming the United States Immunodeficiency Network (USIDNET) patient-consented registry. In 1995, he initiated the long-term tradition of IDF Survey Research. He created a survey of physicians to understand who treated PI, which diseases and numbers treated. He developed, wrote and analyzed the report for three patient surveys, which examined patient attitudes and experiences, as well as three treatment surveys to better understand the experiences of patients on Ig replacement. John has developed numerous other surveys for IDF, and the resulting information is heavily quoted by physicians, researchers, government, and industry. He developed and implemented IDF’s landmark 2006 Population Prevalence of PI in the U.S., which established that the prevalence of diagnosed patients in the U.S. is 1 in 1,200, a number now being used globally. IDF would not be the organization that it is today without the foresight and work of John.

**IDF Art of Nursing Award**

The IDF Art of Nursing Award, new this year, pays tribute to a member of the nursing community who has extensively contributed toward improving the diagnosis and care of patients with PI. In choosing the first recipient, the IDF Nurse Advisory Committee (NAC) selected Debra A. Sedlak, CPNP of Duke University Medical Center, long-time member of the NAC. Ms. Sedlak was educated at Columbia University, the University of North Carolina and Duke, and she has been working with Rebecca Buckley, MD and the other physicians at Duke since 1983, truly taking part in the evolution of diagnosis and treatment of PI over the past 32 years. For many nurses across the country, she has served as a resource and a mentor, teaching many of them much of what they know about caring for patients with PI. Her colleagues say she is a true role model, superb practitioner, and the epitome of what a nurse should be.

To view the Zebra Gala awards ceremony, go to our Vimeo page: https://vimeo.com/idfcommunity/zebra-gala-2015

Award recipients at the IDF 2015 National Conference. From left: Mr. Herbert Petit, Jr.; Rebecca Buckley, MD; John M. Boyle, PhD; William T. Shearer, MD, PhD; Debra A. Sedlak, CPNP.
Rally for SCID Newborn Screening in Louisiana

On the morning of Thursday, June 25, before the IDF 2015 National Conference officially began, energized members of the primary immunodeficiency (PI) community joined forces for a Rally for Newborn Screening for Severe Combined Immune Deficiency (SCID) in Louisiana, raising their voices to ensure that Louisiana babies are not unnecessarily at risk of dying from a curable disease.

Louisiana was the 5th state to begin screening for SCID in 2010 through a pilot program; however, just over 30,000 babies were screened before the state decided to end the pilot in April 2011. Since then, little has been done to reinstate a process that saves lives and reduces healthcare costs. The rally created a unified voice for the PI community to let Louisiana state officials know that all babies deserve a chance at a healthy life and SCID screening needs to immediately come back to the state.

Rally attendees heard from experts in the field of SCID including Marcia Boyle, IDF President & Founder; Ricardo Sorensen, MD, Pediatric Immunologist Louisiana State University School of Medicine Children’s Hospital; Jason Lewis, father of two sons with SCID; Rebecca Buckley, MD, Pediatric Immunologist Duke University School of Medicine; and Carol Ann Demaret, mother of David Vetter, the Boy in the Bubble. Presenters provided personal and scientific testimony about how testing all newborns for SCID saves lives and healthcare costs while preventing physical and emotional pain caused by treatment that comes after late detection.

The urgency of the group’s message was widely heard by the media. IDF representatives participated in television interviews that aired on WAFB TV and WGNO TV in addition to opinion pieces published in the newspapers of record in Baton Rouge and New Orleans to educate the public and politicians about this critical issue.

At the conclusion of the program, over 200 IDF activists contacted public officials, including Governor Bobby Jindal, to let them know how important it is to implement a SCID newborn screening program in Louisiana. If a newborn with SCID is not detected early, the baby has little chance of receiving the lifesaving treatment needed and will likely not see his or her first birthday.

For more information about how you can help urge Louisiana state officials to include SCID screening in the state’s newborn screening panel, contact IDF’s public policy team at idfscidinitiative@primaryimmune.org.
White House Honors IDF’s Marcia Boyle as a “Champion of Change” for Precision Medicine

Precision medicine seeks to change how medicine is practiced, taking into account individual differences, empowering patients and placing them at the center of care, and IDF ePHR and PI CONNECT do just that. With a range of valuable features, IDF ePHR, sponsored in part by CSL Behring, can help patients better manage their health, allowing them to log their symptoms and infections, set goals and notifications and much more—all from their computers, tablets and/or smartphones. To provide the most advanced platform, IDF recently partnered with Get Real Health. IDF expanded upon the power of IDF ePHR after receiving a generous grant from Patient-Centered Outcomes Research Institute (PCORI), creating PI CONNECT—a revolutionary network bringing together patient data from IDF ePHR with clinical data from the United States Immunodeficiency Network (USIDNET) patient-consented registry, which is a program of IDF and is funded in part by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institutes of Health (NIH).

Patients can let their voices be heard by joining conversations in the PI CONNECT Research Forum. Bringing together this information and the patient voice holds great promise to provide researchers further insights about the diagnosis and treatment of PI, ultimately helping to improve quality of life for patients. PI CONNECT has already attracted more than 1,200 individuals who want to make a difference and drive more precise treatment and individualized care.

Marcia has devoted her life to helping people diagnosed with PI, which affect approximately 250,000 Americans. After her son was diagnosed with X-Linked Agammaglobulinemia, Marcia and her husband John, along with the Greenhawk family and her son’s immunologist, created a national patient organization for patients and their families, formally incorporating IDF in 1980. Under Marcia’s leadership, IDF has developed national conferences and patient meetings throughout the U.S. that provide meaningful in-person educational opportunities for individuals and families living with PI. IDF’s full spectrum of educational publications has been a hallmark of the Foundation’s efforts; these publications have been heralded as the best patient resources about PI in the world.

Marcia remains a steadfast champion for those living with PI through IDF’s ongoing advocacy, education and research initiatives. IDF ePHR and PI CONNECT are truly on the cutting edge of precision medicine, part of a national movement that will help researchers find answers and ultimately individualize treatment to provide better outcomes for patients.

Learn more about the White House Champions of Change program at www.whitehouse.gov/champions. For more information about the Precision Medicine Initiative, visit www.whitehouse.gov/precision-medicine.
The Immune Deficiency Foundation (IDF), at its core, believes that individuals living with primary immunodeficiency diseases (PI) have the power to impact research, the power to improve outcomes and treatments for the entire community. The power is in PI CONNECT, the IDF Patient-Powered Research Network.

Users of IDF ePHR, the online personal health record for individuals with PI, have the opportunity to consent into PI CONNECT, which joins the de-identified information users enter into their IDF ePHR with the United States Immunodeficiency Network (USIDNET) patient-consented registry that contains clinical data from more than 4,500 individuals with PI. Bringing together this information through PI CONNECT gives researchers valuable insight into the patient experience.

In 2014, IDF was initially approved for a funding award for PI CONNECT from the Patient-Centered Outcomes Research Institute (PCORI). And on July 21, 2015, IDF received word that an additional three-year funding award was approved by PCORI, as part of the second phase of the development of PCORnet. This funding award continues PCORI’s support for PI CONNECT’s participation in PCORnet, a large, collaborative research initiative designed to link researchers, patient communities, clinicians, and health systems in productive research partnerships that leverage the power of large volumes of health data maintained by the partner networks. PCORnet will enable the nation to conduct clinical research more quickly and less expensively than is now possible and will ensure that research focuses on the questions and outcomes that matter most to patients and those who care for them.

Joe Selby, MD, MPH, Executive Director of PCORI, presented at the IDF 2015 National Conference and discussed the power of the patient in research. There is a national movement to bring patients and other stakeholders into the research process, and Dr. Selby explained how this can truly benefit how research is conducted.

Users who choose to consent into PI CONNECT not only have the opportunity to be involved in research, but they can also access the online Research Forum, featuring exclusive content, videos of researchers, and live webinars. This online forum is a place where patients can have conversations with other patients and researchers about research issues that are important to them—there are currently over 50 active research discussions underway.

IDF wanted to take these research discussions offline. At the IDF 2015 National Conference, IDF held a PI CONNECT Live! Research Forum, moderated by PI CONNECT Principal Investigator Kathleen Sullivan, MD, PhD of Children’s Hospital of Philadelphia and Vice Chair of the IDF Medical Advisory Committee. Dr. Sullivan explained how the landscape of research is changing and the PI community can be an active participant in research. During this live forum, researchers led valuable discussions on four topics taken directly from the online Research Forum:

- **Transplant Research**
  Ramsay Fuleihan, MD  
  Ann & Robert H. Lurie Children’s Hospital of Chicago

- **Fever and Body Temperature**
  Sergio D. Rosenzweig, MD, PhD  
  National Institutes of Health

- **Ig Therapy: Choosing the Right One, Alternative Administrations**
  Ken Paris, MD  
  Louisiana State University Medical Center

- **Prophylactic Antibiotics**
  Lisa Kobrynski, MD, MPH  
  Emory Children’s Center

Dr. Selby commented about his conference experiences in a follow up blog post on www.pcori.org, “I congratulate the IDF, its leadership, and all of its members. I was inspired by the sense of family and community I witnessed and by the keen interest of patients in contributing to research - for themselves and for future patients.”

So, join in this extraordinary movement and become a part of research. Join PI CONNECT and take your seat at the research table!

To read Dr. Selby’s complete blog post, go to: [www.pcori.org/blog/textbook-example-patient-driven-research](http://www.pcori.org/blog/textbook-example-patient-driven-research).

For more information about PI CONNECT, go to [www.idfpiconnect.org](http://www.idfpiconnect.org).
You can help raise awareness and power research with the 2015 IDF Walk for Primary Immunodeficiency! This year, we hope to reach the $1 million mark, and you can be a part of it. It’s an ambitious goal, but we know your participation will make all the difference and we can achieve it together!

Join us for IDF Walk for PI in the following cities:
- **Boston, Boston Common**: October 4
- **Cleveland, Wade Oval**: October 4
- **Minneapolis, Minnehaha Park**: October 11
- **Philadelphia, Penn’s Landing**: October 18
- **Greater Chicago, Cantigny Park (Wheaton)**: October 25
- **New York City, Foley Square/Brooklyn Bridge**: October 25
- **Los Angeles, Tongva Park**: November 8
- **Houston, Discovery Green**: November 15
- **Fort Lauderdale, Huizenga Plaza**: November 22

In 2015, two community walks, a significant part of our walk program, have been added to the lineup of walk options. Dedicated volunteers create these energetic walks in their community, supplementing the number of the existing IDF-organized walks, listed above.

Come out for a Community Walk near you:
- **Omaha, NE, Miller’s Landing**: September 27
- **Charlotte, NC, Freedom Park Bandstand**: October 24

If you don’t live near one of the sites, you can still participate and make an enormous impact by creating a virtual walk team. As a virtual walker, you will have access to the exact same fundraising tools as those at the physical sites and be eligible for the same incentive prizes.

If you need more incentives, here are six more reasons to get moving for the walks!
- **Raise $100 =** Receive the official 2015 Walk t-shirt
- **Raise $250 =** Receive a Walk hide-away sports bottle
- **Raise $500 =** Receive a Walk lunch tote
- ** Raise $1,000 =** Receive a set of Walk headphones
- **Raise $2,500 =** Receive a Walk knit hoodie
- **Raise $5,000 =** Receive a Walk serenity lounge chair

Last year, we had over 80 members in the IDF Order of the Zebra, and we’re looking to expand! Members of the Order make a major impact on Walk for PI by raising $1,000 or more. Strive to become a member this year and receive special benefits at the walk!

To learn more and register, go to: [www.walkforPI.org](http://www.walkforPI.org).

Thank you to our 2015 National Sponsors:
- **Baxalta**
  National Presenting Sponsor
- **CSL Behring**, **Grifols**, **Horizon Pharma**
- **IgG America**, **ASD Healthcare**, **US Bioservices**
- **Option Care**
  National Food and Beverage Partner
- **PepsiCo**

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- **Option Care**
  National Food and Beverage Partner
- **PepsiCo**
IDF Plasma Partners: Vital to the PI Community

The IDF Plasma Partners Program helps to create awareness about primary immunodeficiency diseases (PI) and show the intertwined relationship between patients, plasma donors and employees in plasma collection centers.

The majority of individuals diagnosed with PI have defects in their immune system’s ability to make antibodies to fight infections. Consequently, they rely on life-long immunoglobulin (Ig) replacement therapy. Ig comes from human plasma and is used to replace the antibodies that are needed to protect them from life-threatening infections.

The process by which human plasma is collected, tested and eventually fractionated into plasma products like Ig is complex. There are many different entities involved in the chain that enable plasma to go from a donor’s vein to a finished plasma product that is used by a person with PI. IDF enjoys a strong relationship with those involved in the different stages of this process, appreciating their commitment to the collection of high-quality plasma, and dedication to the highest levels of safety and quality assurances.

As part of the program, IDF arranges plasma collection center visits for individuals and family members who live with PI to gain a better understanding of the importance of plasma donation. In addition, every year plasma collection centers throughout the U.S. run fundraising and awareness campaigns in support of IDF. Employees incorporate the theme THINK ZEBRA! into creative decorations and fundraising activities, enjoyed by donors and all who visit the centers.

Because the health of individuals with PI and plasma businesses are so connected, IDF considers each company involved a partner in improving the lives of patients. Thank you to our Plasma Partners:

BioLife Plasma Services  •  Biotest Plasma Centers  •  CSL Plasma  •  Grifols

For more information about the IDF Plasma Partners Program, go to: www.primaryimmune.org/idf-plasma-partners-program.

Grifols Presents Donation
During the IDF 2015 National Conference, the IDF Board of Trustees accepted a generous donation from Grifols as part of the IDF Plasma Partners Program. Funds were raised from employees and donors across the country.

CSL Plasma Sets Record
Each year CSL Plasma continues to top their previous donations and set fundraising records. In 2015, CSL Plasma set yet another record for their donation to IDF. During the months of April and May, CSL Plasma donors and employees raised over $100,000.

IDF is grateful for the continued support and generous donations of all Plasma Partners!
A Zebra Tale from the Immune Deficiency Foundation
A Heartfelt Storybook for Zebras of All Ages

The Immune Deficiency Foundation (IDF) proudly announces the publication of *A Zebra Tale from the Immune Deficiency Foundation*, an illustrated storybook written for children living with primary immunodeficiency diseases (PI) and their families to provide hope and encouragement. *A Zebra Tale* 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 PI, discovering that he is a zebra.

Individuals diagnosed with PI often identify with zebras. This is based on an old saying. 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. Individuals with PI are the zebras of the medical world. So IDF says THINK ZEBRA!

*A Zebra Tale* made its debut at the IDF 2015 National Conference with the author and illustrator on hand to talk about the new book. Author Katherine Antilla, a mother of a child with PI, has been a member of the IDF community since 1997. Using her background in education and personal experiences, Katherine developed the story to inspire those living with PI to lead happy, fulfilling lives surrounded by family, friends and others in the IDF community. Illustrator Rebecca Zook is an artist who specializes in acrylic painting. Diagnosed with Common Variable Immune Deficiency, Rebecca put her heart and soul into the illustrations to capture the beauty of the characters and their surroundings. At the conference, they were introduced during the Opening Session and spoke to children in the Youth Program about the creation of the book over the past few years.

“Members of the primary immunodeficiency community have long awaited the publication of *A Zebra Tale,*,” explains Marcia Boyle, IDF President & Founder. “With a touching story created by a mother of a child with primary immunodeficiency and beautiful illustrations, developed by a patient, this storybook was truly a labor of love. It will be a meaningful resource for zebras of all ages, helping them to cope with the emotional impact of living with primary immunodeficiency and to understand that they are not alone.”

IDF is grateful to the American Legion Child Welfare Foundation for their support of this book and to the healthcare professionals, educators, adults and children in the IDF community for their input throughout the creation of the story. Individuals and families can download or order a hard copy of *A Zebra Tale* at [www.primaryimmune.org/idf-publications](http://www.primaryimmune.org/idf-publications).

Author Katherine Antilla (left) and illustrator Rebecca Zook tell children at the IDF 2015 National Conference Youth Program about *A Zebra Tale*. 
IDF School Guide
Be Prepared for the Upcoming School Year

Published earlier this year, the Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases – Third Edition is a valuable resource to have on hand for the school year. IDF developed this guide to help facilitate effective communication between parents, students and school personnel.

Parents often find it helpful to start the school year with copies for their children’s teachers, school nurse, athletic coaches and other school personnel.

To download or order copies, go to www.primaryimmune.org/idf-publications.

This publication was sponsored by Baxalta US Inc.

Follow the IDF Blog

Stay up to date on the latest news and events happening in the primary immunodeficiency community with the IDF Blog. You can easily sign up to receive notifications when a new post is live. Go to: www.primaryimmune.org/blog.

Have a Question? Ask IDF!

The Immune Deficiency Foundation (IDF) fields hundreds of questions each month from individuals and families living with primary immunodeficiency diseases (PI). We assist those living with PI with a broad array of services including inquiries related to diagnosis, treatment, health insurance, peer support and literature requests.

If you have a question, please contact IDF. Whether you want to know more about health insurance, want to connect with someone going through similar experiences, or have other general questions about living with PI, you can always ask IDF!

- Go to www.primaryimmune.org/ask-idf.
- Call 800-296-4433 (Monday - Friday, 9 a.m. - 5 p.m. ET).
- E-mail info@primaryimmune.org.
Clinical Focus on Primary Immunodeficiencies: Subcutaneous Immunoglobulin Replacement

The Immune Deficiency Foundation (IDF) is pleased to present the new edition of Clinical Focus on Primary Immunodeficiencies: Subcutaneous Immunoglobulin Replacement.

As use of subcutaneous immunoglobulin (SCIG) continues to grow in the U.S., more clinicians are using this delivery system for their patients and may not understand all the subtleties and importance of this method and the proper administration. There are also many questions about how to deal with side effects and reactions. Not only does this publication offer appropriate guidelines for SCIG, but it also answers commonly asked questions about SCIG and provides in-depth details about the many options for SCIG administration.

This publication, released at the IDF 2015 National Conference, was authored by Francisco A. Bonilla, MD, PhD, Director, Clinical Immunology Program, Boston Children’s Hospital, and Associate Professor of Pediatrics, Harvard Medical School; and Carla Duff, CPNP, MSN, CCRP, Advanced Registered Nurse Practitioner, University of South Florida; and edited by Mark Ballow, MD, Director, Allergy and Immunology Training Program, University of South Florida/All Children’s Hospital. It was approved by the IDF Medical Advisory Committee.

You can download a PDF version or order copies at www.primaryimmune.org/idf-publications, or if you prefer, contact IDF at 800-296-4433 or idf@primaryimmune.org to order hard copies.

This publication was funded by an unrestricted educational grant from CSL Behring.

Nurses: Earn 5 Free CE Credit Hours!

IDF Online Continuing Education Course for Nurses: Primary Immunodeficiency Diseases and Immunoglobulin Therapy

The Immune Deficiency Foundation (IDF) is proud to offer this Online Continuing Education Course, developed as an initiative of the IDF Nurse Advisory Committee. This free, accredited course enhances the knowledge of the nurse clinician by providing an update on primary immunodeficiency diseases, immunoglobulin (Ig) therapies and the nurse’s role with these therapies. Any nurse who is involved with administration and management of Ig therapy or the disease states where Ig is used would find this program very informative and applicable to practice.

Go to www.primaryimmune.org/healthcare-professionals/continuing-education-course-for-nurses/.

This course is sponsored by CSL Behring.

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IDF Advocacy Day 2015
Fighting for The Patients’ Access to Treatment Act

On April 30, 2015, the Immune Deficiency Foundation (IDF) held its annual Advocacy Day in Washington, DC. Over 60 members of the primary immunodeficiency (PI) community (pictured above) made their way to Capitol Hill to advocate on behalf of those with PI and in support of The Patients’ Access to Treatment Act (PATA), HR 1600, which seeks to restrain out-of-pocket costs for patients who use expensive specialty drugs, such as immunoglobulin (Ig) therapy—a life-saving treatment for many patients with PI.

HR 1600 is bipartisan legislation that will help ensure patients with chronic, disabling and life threatening conditions access to the treatments they need. It would limit out-of-pocket costs for medications in a specialty drug tier (typically Tier IV or higher) to the dollar amount applicable to the drugs in a non-preferred brand drug tier.

Dedicated IDF advocates, from teens to retirees representing more than 30 different states, attended over 135 meetings to garner support for HR 1600. They put a face to PI and emphasized why the passage of HR 1600 is so critical to the PI community. The results of their hard work were evident soon after, as several legislators made commitments to co-sponsor HR 1600.

To learn more about showing your support for HR 1600, go to: www.primaryimmune.org/idf-advocacy-center.

Celebrate IDF’s 35th Anniversary

The traditional 35th anniversary gift involves either coral, jade, or emerald. While we would certainly be thrilled if someone sent us some loose emeralds, all three of those would clash with our zebra stripes. We would, however, be thrilled if you made a different type of anniversary gift.

A truly meaningful way to commemorate IDF’s first 35 years would be to use the enclosed envelope or to go to www.primaryimmune.org/give to make a gift of $35, $350, $1,350 or $3,500 (or any other amount that you choose) before December 31 in honor of IDF’s anniversary. Your anniversary gift will help us to ensure that IDF has the resources necessary as we prepare for the next 35 years.

If IDF has touched your life at some point over these last three decades, we hope that you will help us celebrate this milestone with a gift to the entire primary immunodeficiency community.

To donate, go to www.primaryimmune.org/give. Thank you!
In Memory of
Dr. Víctor Grífols i Lucas (1919–2015)

Dr. Víctor Grífols i Lucas passed away in Barcelona on June 1, 2015. He was one of the founders of Laboratorios Grifols and was President of the Grifols group of companies from 1985 to 2001. Dr. Grífols was a driving force behind the application of Good Manufacturing Practice guidelines, and was responsible for taking the first steps in obtaining the company’s initial license from the FDA. He was the embodiment of a whole set of values: he was good, kind, discrete, modest, friendly, enterprising, committed to the company and, above all, honest.

Dr. Grifols will be added to the Immune Deficiency Foundation Remembers plaque, a perpetual plaque located in the IDF office to remember the individuals with PI, parents, medical professionals, and others who we have lost who were part of our community.

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
2/1/2015 – 7/1/2015

Rhiva Brooks                      Thomas Marbach
Bud Calkins                       Kristin Martin
Lisa Codispoti                    Alan McGovern Jr.
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Pat Douglas                       Pattiani Phillips
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Madelyn Labrecque                Tristan Svare
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Frank Lazzaro                     Joan Turner
Michael LeBien                    Eric Weintraub
Jennifer Lipschultz               Craig Zolotorow

All donations help IDF improve the diagnosis and treatment of patients 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
Mail: Immune Deficiency Foundation
      110 West Road, Suite 300
      Towson, MD 21204

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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, Director of Development, at jboyle@primaryimmune.org to learn more about becoming a member of the IDF Legacy Society.
IDF ADVOCATE

Editor
Christine M. Belser

Medical Editor
Rebecca H. Buckley, MD

Managing Editor
Kara M. Moran

Senior Editor
Adam Freestone

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IDF Advocate
Immune Deficiency Foundation
110 West Road, Suite 300
Towson, Maryland 21204

Toll-Free: 800-296-4433
Direct: 410-321-6647
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For an Updated IDF Calendar of Events, Visit
www.primaryimmune.org/event-calendar.

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Join us for IDF Walk for PI 2015!

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Read more on page 9!

www.walkforPI.org

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