PI CONNECT, the new IDF Patient-Powered Research Network, joins the information patients enter into IDF ePHR, the online personal health record for patients with primary immunodeficiency (PI) with the United States Immunodeficiency Network (USIDNET) patient-consented registry, which contains clinical data on several thousand patients with PI. Bringing together this information through PI CONNECT gives researchers valuable insight into the patient experience—you are truly a unique resource who can help power research!

IDF Medical Advisory Committee Vice-Chair Kathleen Sullivan, MD, PhD of Children’s Hospital of Philadelphia is the PI CONNECT Principal Investigator and shared her thoughts about this innovative research network and how it will impact the PI community:

Q. Why is PI CONNECT important to patients with PI?
A. Primary immunodeficiencies are uncommon, and no one center has a sufficient number of patients to understand the full spectrum of the illnesses or to compare treatment outcomes. PI CONNECT is a way to leverage technology and patient numbers to answer every day questions we all have, such as, What treatment works the best? What happens later on? What do I need to watch out for?

Q. How does PI CONNECT enable patients to be a part of research?
A. Patients are central to every research effort, but today patients can help focus research efforts through the IDF PI CONNECT Research Forum. Who knows more about the important questions than the patients themselves? The forum is a blog-style interaction site where researchers and patients can exchange ideas about important questions that need to be answered. In addition, there are research updates available to physicians, researchers and patients. We plan webinars to facilitate interactions between patients and researchers.

Q. What do you hope for PI CONNECT?
A. I know my patients all want to know, What happens in 10 years? Is this really the best treatment? Why aren’t my antibiotics working anymore? PI CONNECT can answer those questions. When we look at the health information from thousands of patients, we can get a much better idea of the overall landscape of medical problems and can compare what has worked and what hasn’t worked. Together, patients and researchers will collaborate to answer relevant questions and improve the care for everyone.
How Do Patients Register for PI CONNECT?

Patients can create an IDF ePHR account and join PI CONNECT in 4 Easy Steps!

1. **Create Your IDF ePHR Account** – Go to www.idfephr.org and click “Create Account.” You’ll be asked to enter your basic information. IDF ePHR is an easy way to safely and securely store your information in one place.

2. **Begin Your First Record** – You can create records for your whole family, but the first record you begin with should be for the person with PI. All other records that follow do not require a PI diagnosis. Be sure to enter all required information, and accept the terms and conditions. Those who have a PI will be asked to consent into PI CONNECT.

3. **Join PI CONNECT** – Join PI CONNECT, the IDF Patient-Powered Research Network, and be a part of research! You will be asked to join PI CONNECT by giving your consent to allow patient-entered data from your IDF ePHR to enter the United States Immunodeficiency Network (USIDNET)*. Your data will be de-identified. Once you join, you can participate in research conversations on the IDF PI CONNECT Research Forum.

4. **Start Using the IDF ePHR** – Your IDF ePHR is your personal health record. Record your medications, track your infusions, set goals, reminders and notifications—make it work for you. Customize your ePHR and sync with Microsoft HealthVault to access information from various labs, pharmacy systems, personal health devices and health resources. Make time with your clinician more beneficial by sharing organized, comprehensive information from your ePHR. Most importantly, use IDF ePHR to help you live a healthy life!

Go to www.IDFePHR.org and get started today!

*PI CONNECT joins the information you enter in your IDF ePHR with the United States Immunodeficiency Network (USIDNET) patient-consented registry, containing clinical data on several thousand patients with PI. USIDNET, a program of IDF, is a research consortium established to advance scientific research in the field of primary immunodeficiency diseases. The current focus of this initiative is on the primary immunodeficiency disease registry, and education and mentoring for young investigators. USIDNET is funded in part by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institutes of Health (NIH) an agency of the Department of Health & Human Services. For more information, visit www.usidnet.org.

Take charge of your health with IDF ePHR, the electronic personal health record designed for the primary immunodeficiency (PI) community.

**With IDF ePHR, you can:**
- Take advantage of easy-to-use tools to help you improve your health and organize your info.
- Record the basics, like your diagnoses, medications, supplements, Ig infusions.
- Track your health and fitness goals, set reminders and notifications.
- Access IDF ePHR from anywhere—your computer, tablet or phone. The site is mobile responsive, and the IDF ePHR app will soon be available!
- Enter as much or as little information as you want, including your symptoms, infections, allergies and more.
- View your progress in charts and graphs.
- Sync your IDF ePHR with your Microsoft HealthVault account to access information from various labs, pharmacy systems, personal health devices and health resources.
- Keep your medical info safe, secure and private at no cost to you.

**Streamline Your Info**

Like many patients with PI, you probably keep track of large quantities of medical information. IDF ePHR was designed specifically for patients with PI, so you can streamline how you manage and organize your health information.

- Create, share and print reports for your healthcare provider.
- Utilize chronic disease management tools and keep track of all conditions.
- Download medical records through Blue Button+ from participating providers.

An added benefit of IDF ePHR is the opportunity to be a part of research by joining PI CONNECT, the IDF Patient-Powered Research Network.

**Now is the time**—improve your health and power research! Create an account today: www.IDFePHR.org.

For more information, e-mail info@idfephr.org or call 800-296-4433.
Join the Immune Deficiency Foundation (IDF) in New Orleans for our eighth national conference as we gather in the Crescent City! The IDF 2015 National Conference will take place at the Hyatt Regency New Orleans on June 25-27, 2015. After a successful IDF 2013 National Conference, held in Baltimore, MD, with over 1,200 people from 12 countries, 44 states and Washington, DC, we’re preparing to do it again!

The IDF National Conference is our preeminent event, held biennially in cities throughout the U.S., and is a platform for all facets of the PI community. From healthcare professionals to specialized life management experts, patients and family members are presented with an unsurpassed opportunity to learn from those on the cutting edge of research and treatment. The networking and entertainment venues, as well as the times to share ideas, support and laughs, are bound to create memories to last a lifetime for attendees of all ages. The IDF 2015 National Conference is packed with sessions and activities that we hope you enjoy!

**IDF 2015 National Conference Highlights**

- Welcome to New Orleans Reception
- Healthcare and Life Management Presentations
- IDF Zebra Gala
- IDF Night at Mardi Gras World
- IDF Exhibit Hall Featuring Products and Services for the PI Community
- Youth Programs for Our Younger Attendees
- Thursday Symposia for Chronic Granulomatous Disease and Wiskott-Aldrich Syndrome
- Professional Medical Education Program by the Clinical Immunology Society

**IDF 2015 National Conference**

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**2015 Early Registration Fees (Register before April 30, 2015)**

- Individual – $125
- Family of 4 – $205
The Immune Deficiency Foundation (IDF) continued its second year of success with the 2014 IDF Walk for Primary Immunodeficiency as over 2,800 people participated and raised more than $375,000. Our sponsor commitments brought the overall funds raised to over $700,000 in support of vital IDF programs and services. Boston, Houston and New York joined our existing sites in Chicago, Los Angeles, and Philadelphia for a total of six events, all of which had beautiful weather this year.

In addition to serving as a fundraiser for IDF, the walks also generated grassroots awareness and high level media attention in each host city. In Philadelphia, WPHL 17 TV ran a feature story in advance of the walk, sharing details about PI and how people could get involved. The Chicago walk was the focus of ABC 7 TV’s Talkback Live segment, where Chicago Walk Chair Amy Walsh and her son Aidan were interviewed live from the event site. Multiple media outlets covered the Houston walk with Carol Ann Demaret and Yvette Shorten sharing their families’ journey with PI and how they are helping to raise awareness. Additionally, Telemundo News filed a story on the walk, marking one of the few, if not only, Spanish-language news broadcasts about PI. In New York, committee member Harper Spero coordinated the broadcast of over 100 public service announcements on five Clear Channel Radio Stations throughout the metro area. We would also like to thank Bill Hindin of New York and Megan Ryan of Houston for securing Mayoral proclamations commemorating their cities’ walks, another way to raise awareness. Each walk attracted significant media coverage that not only helped to raise the profile of the walks but also directly educated the public about the diseases and IDF.

In addition to the six primary events, people from across the country raised awareness and thousands of dollars through the Nationwide Virtual Walk, which ran until December 31, 2014.

IDF is incredibly grateful for the funds that were raised, the awareness of PI that was generated, and the enthusiasm for this increasingly successful initiative. We hope that you will follow IDF Walk for PI on Facebook to stay up to date in 2015 and contact walk@primaryimmune.org with any questions.
Coming in 2015

Three new walks in Cleveland, Minneapolis and South Florida will be added to the walk sites in Boston, Greater Chicago, Houston, Los Angeles, New York and Philadelphia!

IDF Order of the Zebra

A new addition to the 2014 walks was the IDF Order of the Zebra. Individuals who raised $1,000 or more for the walk became members of the Order and made the greatest impact upon the success of each walk site. IDF is grateful for its current Order members and looks forward to expanding the group’s ranks in 2015. Please visit www.walkforPI.org to see the list of Order members.

IDF Walk for Primary Immunodeficiency Sponsors 2014

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Biofusion*
Ethical Factor RX
Soleo Health *****

*Two sites  ***Four sites  ****Five sites  *****Six sites

Held in Six Cities

$700K for IDF

Philadelphia Walk Committee Members with Marcia Boyle, IDF President & Founder. From left, Sara Daniele, Judy Kozulak, Chuck Lage, Marcia Boyle, the new zebra mascot and Amanda Merriell.

Team “Take the Lead with Ethan and Reed” at IDF Walk for PI in Greater Chicago.

LA Walk chair Kristy Cacucciolo, along with her son Justin and daughter Nicolette.

Ashanthi DeSilva, the first human gene therapy patient, along with Greater Chicago Walk committee members Zina and Randy Berryhill.
An Extraordinary Bond: “They Will Never, Ever Feel Alone Again Because They Have Each Other...”

IDF Peer Support Connects Moms and Daughters

“They will never, ever feel alone again because they have each other, and they’re sisters. Always.” Jana Trueb of Oregon holds back tears as she describes the genuine friendship between her 16-year-old daughter Olivia and 17-year-old Holli Napper of Alabama.

The teenagers, both diagnosed with Common Variable Immune Deficiency (CVID), became friends after their moms met through IDF Peer Support. This program connects patients and families living with primary immunodeficiency diseases (PI) who are going through similar experiences. After a simple phone call, these two women developed an extraordinary bond that brought together two families, even though they live over 2,700 miles apart.

It all began when IDF Volunteer Jane Napper, Holli’s mom, was asked to reach out to a mom in Oregon who also had a daughter around the same age with the same diagnosis. The moms talked on the phone and immediately became close friends. Jana says that Jane is her “sister from another mister… I don’t know where I’d be without her. I can text her at 1 a.m.” And despite the two-hour time difference, Jane says that those texts never go unanswered—they are truly there for each other. “We know we’re never alone especially with the IDF family behind us,” Jane explains.

Naturally, the moms thought that their daughters would get along too. The girls began talking on the phone, writing letters and chatting on Facebook and Skype. It turns out that Olivia and Holli have many things in common—they love animals and the band R5. They like the same food, and both have animal-themed rooms—Olivia’s is decorated in Dalmatians, Holli’s in horses.

“To listen to Holli and Olivia talk for that first time… it was like a normal kid being normal,” says Jana. The girls talk about everything. Even with Holli’s Southern accent, they understand each other better than anyone else.

The moms had the opportunity to meet each other in person at an IDF Patient Education Meeting in North Carolina. “We wouldn’t let each other go,” Jana says. The opportunity for the girls to meet took a little more planning. This past September, the Nappers, Holli along with her mom and dad, decided to make the long trip from Alabama to the IDF Retreat in Portland, OR, and it was the perfect opportunity to surprise Olivia.

Holli says, “After a really long plane ride… we pulled up to her house and Olivia was outside. We were so happy. We ran to each other and hugged each other.” Olivia says, “It was a huge surprise!”

Both the moms and daughters encourage others to get connected with IDF. For teens and IDF, Olivia explains, “You will find friends in the teens that you wouldn’t expect to click with them on the level that you do.”

Jana says, “For moms, dads, caregivers, you are not alone. There are so many avenues through IDF that you can be brought together with people who are going through the same things that you are, the same struggles you face every day. There’s advice—medical, emotional—that is priceless through this Foundation. If you feel like there is nowhere for you to go, please go to IDF.”

Jana agrees, “When you google ‘immune deficiency,’ IDF comes up first. It’s probably the smartest thing to click on because it’s all encompassing. They do educational days… Even if you learn one thing, it’s so worth it. Even if it’s something little, it’s priceless.”

The girls truly feel like they’re sisters, and the moms feel the same. “The friendship and the camaraderie and the support that we have been able to get from each other over the last years has just been amazing. We have truly, truly been blessed… Our families have so much in common that it’s like picking up the phone and calling the neighbor instead of them being across country... the support has been wonderful. We couldn’t ask for more.”

To view a video of Jane and Jana’s story, go to IDF Reel Stories: www.youtube.com/idfreelstories.

How do I participate in the IDF Peer Support Program?

It’s easy… just contact IDF through “Ask IDF” at www.primaryimmune.org/ask-idf, or call 800-296-4433. The IDF Peer Support Program is a caring community that connects people and patients who share similar relationships to primary immunodeficiency (PI). Participation in the program gives you the opportunity to interact with one of IDF’s peer support volunteers, who is a trained volunteer with personal experience living with PI. Perhaps you want to speak with a patient living with the same type of PI or wish to contact an experienced parent of a child with PI. Maybe you seek to network and share ideas and experiences with someone who lives in your state. An IDF staff member will contact you and get to know you and your needs, and make arrangements for a peer support volunteer to contact you by phone or e-mail, however you prefer.

This free resource is for anyone personally affected by PI—a patient, parent or other family member, friend or caregiver. And you can take comfort in knowing your communications and correspondence will be held in the strictest confidence. Remember, you are not alone. IDF is here to help.

The IDF Peer Support Program is supported by charitable donations from Abbvie, Baxter International Inc., CSL Behring, Grifols, Biotest Pharmaceuticals, IgG America / ASD Healthcare / US Bioservices, Octapharma, Sigma-Tau Pharmaceuticals.
Proof Positive: Study Confirms the Need for Early Screening and Intervention for SCID

The publishing of a landmark study in The Journal of the American Medical Association highlights findings of a large group of contributors* led by Jennifer M. Puck, MD, senior author of the study and a renowned Severe Combined Immune Deficiency (SCID) expert who is also a member of the IDF Medical Advisory Committee. The study, “Newborn Screening for Severe Combined Immunodeficiency in 11 Screening Programs in the U.S.,” published August 20, 2014, presented data from a wide range of screening programs, established an incidence rate based on populations, and discussed the significance of early intervention.

Success of SCID Newborn Screening

This retrospective study of more than 3 million infants from 11 newborn screening programs confirms the undeniable value of early detection and treatment of SCID. When diagnosed early following screening, 92% of infants with SCID received early intervention, such as bone marrow transplants, and survived. The study also found an incidence of one case of SCID per 58,000, nearly twice the previously estimated rate of one in 100,000. Newborn screening for SCID is performed using measurement of T cell receptor excision circles (TRECs). Absent or low TREC levels can indicate insufficient T cell production characteristic of SCID, but can also flag infants with non-SCID conditions in which T lymphocytes may be dangerously low.

Dr. Puck remarked on the unique size and comprehensiveness of the study, “Assembling data from over 3 million infants screened has not only given the most accurate estimate of the true frequency of SCID (1/58,000 births), but has proven that early treatment optimizes survival.” Further, she added, “What’s also interesting is that although the individual states each developed an independent approach to TREC testing and follow-up, all approaches successfully identified SCID.”

One factor that hinders early detection of SCID without newborn screening is frequent absence of any family history. Previous studies indicated that fewer than 20% of infants with SCID have had known affected relatives. “Although it’s always important to ask about a family history, most SCID patients are sporadic,” says Dr. Puck.

Genetic Types of SCID

There are at least 13 different genetic defects that can cause SCID. Experts previously believed that nearly half of infants with SCID had the X chromosome-linked variety caused by a mutation in the common gamma chain of lymphocyte receptors. However, according to the article, newborn screening data found only 19% with this genetic form. Dr. Puck points out, “Our understanding has changed due to having higher patient numbers and unbiased, population-based ascertainment. Data from universal screening is more accurate than previous assessments, which were derived only from infants who were treated at specialized transplant centers.” It will be interesting to see whether other countries have similar results from SCID newborn screening. Unquestionably, there are population subgroups where a specific gene and a particular mutation causes SCID at more frequent rate, for instance within the Navajo nation and in Amish communities in the U.S. (Continued)

Non-SCID Conditions

The breadth of this study has also allowed for the identification of non-SCID conditions marked by low T lymphocytes at birth; some of these also require early intervention. According to Dr. Puck, “The infants with non-SCID conditions in whom TREC testing led to diagnosis of low T cells represent a spectrum of disorders. Some had congenital syndromes, such as DiGeorge/chromosome 22q deletion, trisomy-21, cartilage hair hypoplasia, CHARGE syndrome, ataxia telangiectasia or other multisystem disorders in which the immune problems are accompanied by problems in other organ systems.” If these conditions are very severe and discernable with low T cell counts and low T cell function, they should be followed by pediatric immunologists. Avoidance of live vaccinations such as the rotavirus vaccine may be prudent, and other interventions may be required.

This study by Dr. Puck and colleagues adds weight to the IDF SCID Newborn Screening Campaign to see universal newborn screening for SCID implemented across the nation and provides proof positive that the TREC test is an effective instrument to identify SCID early enough to deliver life-saving intervention. As more and more states are following the 2010 U.S. Department of Health and Human Services recommendation that every state include this vital screening, this new study has the strength to answer lingering questions and provide an added push for states that have been slow to implement the practice. Newborn screening for SCID saves lives.

For the latest information, visit the IDF SCID Newborn Screening Campaign Blog: www.idfscidnewbornscreening.org.

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The introduction of intravenous immunoglobulin (IVIG) products in the 1980s led to a revolution in the therapy of antibody deficiency. With this innovation it finally became possible to safely give enough immunoglobulin (Ig) to an immunodeficient individual to bring the serum level into the normal range, and its use soon became the standard of care.

However there were some individuals who experienced significant problems with the need for regular access to veins sufficient to permit large volume infusions. Infants, children, the elderly and others with “bad veins” sometimes needed to undergo multiple uncomfortable attempts to find a suitable vein or sometimes to even forego their treatments because of lack of adequate venous access.

Clinical situations are common where reliable venous access is essential for the delivery of needed drugs and blood products on a weekly or less frequent schedule. This challenge has led to the development of semi-permanent infusion ports connected to a large central vein that are then implanted under the skin and accessed by inserting a needle through the skin into the device’s subcutaneous port.

Understandably when IVIG became available, some individuals began to ask about these devices to avoid problems with their monthly Ig infusions, especially if they had limited venous access. Infusion ports implanted under the skin became quite popular and were often recommended by some providers.

With increasing experience, however, most immunologists now do not recommend the use of infusion ports except in extreme situations. The reasons for this reluctance are several. First is the risk of development of a systemic or blood stream infection that implanted catheters carry. These infections can be fatal. Any foreign material in the body causes a local reaction, and this makes it easier for bacteria to take hold in that location. Therefore the port and catheter produce a local environment where any microorganism that enters the body can become more easily established and develop into an active infection. Microorganisms from the skin can gain entry to the port during the needle puncture through the skin to reach the port for infusion and then infect the port and travel down the lumen of the catheter tube and enter a vein causing systemic infection.

Whenever an infection is suspected, the port/catheter should be cultured to determine if it has become colonized with bacteria or fungi. Further, if the patient develops a significant fever, they will be presumed to have an infection and will need to be treated with antibiotics until cultures return and infection is ruled out. If the catheter becomes colonized, prolonged antibiotic treatment may be needed and the catheter/port may need to be removed and replaced to clear the infection. Some types of infections are more likely to result in catheter removal than others and colonization with Candida albicans can be particularly problematic. With some types of infection the port needs removal in over 80% of cases. Routine regular care to maintain the port in good condition is required and may involve irrigating the port with heparin, saline or another solution daily, weekly or monthly depending on the particular port used.

All of these devices also have a certain intrinsic failure rate and will need surgery to remove and replace them. This adds expense and has its own slight risks like any surgical procedure. Another significant issue of concern is that permanent or indwelling catheters have the risk of promoting thrombus or clot formation. This is particularly relevant to the individual receiving IVIG because the product itself has in the past been occasionally associated with thromboembolism. Thromboembolism is one of the listed warnings contained on the IVIG product label and has caused serious blood clots in the lungs and rarely even sudden death. Adding an infusion port makes this complication of IVIG more likely.

The amount of data on the frequency of these complications in patients with primary immunodeficiency diseases (PI) and infused catheters and ports is very limited. For an example of data available in patients with other medical conditions, a careful study of 132 cancer patients with implanted ports followed for at least one year, found that complications occurred in 26% of the study group. These ranged from early complications associated with surgery to implant the device and included collapsed lungs and excessive bleeding during the surgery. Later complications included system blockage, thrombosis, infection, catheter defects, local leakage and necrosis of the skin at the site of the port.

Given the very serious risk involved with the use of implantable ports, their use must be reserved for situations where the benefits are considerable and not just for convenience.

So what alternatives are available for the patient with poor venous access who needs immunoglobulin replacement treatment?

One alternative that is gaining increasing popularity amongst patients needing Ig replacement treatment is to receive their Ig infusions subcutaneously. In fact, the most recent patient survey conducted by IDF indicates that 45% of respondents are now receiving their infusions at home with self-administered subcutaneous immunoglobulin (SCIG).

SCIG has several features that contribute to this increasing rate of its adoption. In general it has been observed that there are fewer infusion related reactions to SCIG than there are to IVIG infusions. Some people find it more convenient to use since they can easily adjust the timing of infusions to match their own schedule preferences and can often carry on with certain activities that are not possible when tethered to an IV. Serum levels of IgG tend to remain stable during the week between infusions so that recipients do not experience the “week before” symptoms common in some IV recipients. SCIG has also been used successfully to treat all age groups from infants as young as a few months to the elderly.

And finally, SCIG infusion does not require venous access to be able to achieve normal therapeutic levels of IgG. One of the professional groups that focus their activities on PI is currently considering a proposal to recommend against the use of infusion ports for PI except in unusual circumstances because they are no longer needed and, therefore, it is not necessary to accept any risk associated with their use in the patient with antibody deficiency.

In all cases, patients and caregivers should consult their healthcare providers. Each patient’s condition and treatment is unique. This article cannot be applied safely to any individual case and should not be used as a substitute for professional medical advice.
“Things to Consider When Choosing a Health Plan”
Watch New IDF Video

When you are choosing a health insurance plan, whether it’s through the marketplace or through your employer, you need to make sure it’s the right healthcare plan for you and your family. Watch the new video “Things to Consider When Choosing a Health Plan” for help in making the best possible choice in selecting a private health insurance plan. You can also download the IDF Health Insurance Toolkit, complete with updated information, tips and worksheets.

For the video and the toolkit, go to www.primaryimmune.org/services/patient-insurance-center/. Visit www.healthcare.gov for more information about the health insurance marketplaces.

Now Accepting Requests for IDF & USIDNET LeBien Visiting Professor Program

To help improve the diagnosis and treatment of primary immunodeficiency diseases, the Immune Deficiency Foundation (IDF) invites teaching hospitals to benefit from its free educational program for teaching hospitals throughout the U.S.—The IDF & USIDNET LeBien Visiting Professor Program. This popular program provides a leading clinical immunologist to conduct Grand Rounds and present at educational activities, such as bedside rounds, house staff presentations and medical resident conferences.

Requests for the IDF & USIDNET LeBien Visiting Professor Program for 2015 are now being accepted. Simply write a brief (one page) Letter of Request stating your reason to participate in the program and how your students would benefit. Please include a tentative list of teaching and clinical activities. Submit this information to idfvisitingprofessor@primaryimmune.org by January 16, 2015. Contact IDF should you have any questions: 800-296-4433.

The IDF & USIDNET LeBien Visiting Professor Program is supported by charitable donations from Abbvie, Baxter International Inc., CSL Behring, Grifols, Biotest Pharmaceuticals, IgG America | ASD Healthcare | US Bioservices, Octapharma, Sigma-Tau Pharmaceuticals.

Enrollment for the Medicare IVIG Demonstration Project Is Still Open

Enrollment for the Medicare IVIG Demonstration Project is still open!

New applications for participation in the Medicare IVIG Demonstration Project will be accepted on a rolling basis until the project reaches the statutory limit on funding and/or enrollment.

For complete details and how to enroll, go to www.medicarenhic.com.

IDF Flu Information for 2014-2015

For the 2014-2015 Flu Season, the Immune Deficiency Foundation (IDF) has published recommendations for patients with primary immunodeficiency diseases (PI) and their families, including prevention, vaccination and creating a family plan.

For IDF’s recommendations, go to www.primaryimmune.org/flu.
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IDF Organizes New Coalition to Advocate for Patient Safeguards for ‘Biosimilar’ Drugs

The Immune Deficiency Foundation (IDF) joins with 22 other leading patient advocacy organizations to launch Patients for Biologics Safety & Access (PBSA), a coalition dedicated to protecting patient access to safe and effective biologic medicines. PBSA members, who represent millions of patients living with serious, life-threatening and difficult-to-treat conditions, plan to ensure that there are adequate patient safety protections in place as the Food and Drug Administration (FDA) creates the regulatory pathway for biosimilar medications. PBSA is the only coalition of patient advocacy organizations speaking solely from the patient perspective.

Biologics are medicines made from living organisms and are far more complex than traditional chemical drugs. Immunoglobulin replacement therapy is an example of a biologic medicine because it is made from blood plasma. Even slight variations in the manufacturing of immunoglobulin can result in serious, adverse events in patients. As part of the Affordable Care Act (ACA), Congress enacted the Biologics Price Competition and Innovation Act (BPCIA) establishing authority for FDA to review and approve a new category of drugs known as biosimilars.

Biosimilars are highly similar but not identical to biologic medicines. Because of the uniqueness and complexity of biologics, biosimilars are not and cannot be generic copies of biologic medicines.

Member organizations founded PBSA around the following guiding principles:

- Patients must have access to safe and effective biologic and biosimilar medicines;
- Prescribers and patients should have all the information necessary to make a fully informed choice about whether to use an innovative biologic or biosimilars;
- Steps must be taken to assure appropriate tracking of adverse events for all biologics, including biosimilars, so that safety problems are promptly and accurately identified;
- Biosimilars should have unique nonproprietary names to eliminate confusion, allow prescribers to accurately track the therapeutic agent in a patient’s medical record and quickly trace a product to an adverse event.
- Biosimilar pathways should support innovation and ensure incentives remain to bring new therapies to market for patients.

As the FDA creates a regulatory pathway to market for biosimilars, IDF wants to make sure the voices and interests of patients are front-and-center.

For more information about PBSA and complete list of member organizations, please visit www.BiosimSafety.org.
WITH GRATITUDE

MEMORIAL GIFTS
6/16/14 - 11/14/14

Tamara Allard
Luke Altobelli
Bud Calkins
David Carey
Lisa Codispoti
Emily DeSimone
Timothy Else
Ladyne (Deanie) Emmerich
Daniel Fratto
Peggy Fulton
Janese Galuzka
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Dallas Grice
Bonnie Harris
Ann Hartwell
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Rebecca Keller
Brian Krzystof
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Rachel Roy
Denise Ryan
Jennifer Sampson
Donald Schrock Jr
Matt Seals
Joan Smerge
Arian Sprague
Mary Stout
James Trillo
Tim Turner
Timothy Turner
Roman Wallace
Eric Weintraub
Diane Williams

IN MEMORIAM

Michael LeBien, the son of Robert and Sara LeBien, died November 9, 2014. Mike is also survived by his wife, 5-year-old son, 8-month-old daughter, brother and family. Because of Mike’s diagnosis of Common Variable Immunodeficiency Disease (CVID), Bob and Sara have been actively involved in IDF since the early 1980’s. In addition, Bob started the International Patient Organization for Primary Immunodeficiencies (IPOPI) and served as the chair for a number of years, and Sara is well known as the author of IDF’s children’s book, Our Immune System.

Eric Weintraub died October 24, 2014 surrounded by parents, Susan Brecher and Michael Weintraub, and sister Rebecca. Eric, who had CVID, connected an incredible number of families living with CVID online and enabled them to learn from and support each other. He attended IDF meetings and was always positive and supportive to others. We are immensely grateful for the lives that were touched and changed because of his efforts.

Your Gifts Help Support Vital IDF Programs and Services

Thank you to all those who made a gift to the Immune Deficiency Foundation in 2014! Thousands of people living with primary immunodeficiency diseases turn to IDF for education, resources and support. Your gift helps us continue providing these vital programs and services to individuals, families and healthcare providers as their needs expand.

To make your 2015 gift online, please visit: www.primaryimmune.org/give.

To make your gift by check, please use the enclosed envelope and make your check payable to “Immune Deficiency Foundation.”

IDF also gratefully accepts gifts of stock and other securities. For more information about making your gift in those or any other ways, please contact John Boyle, Director of Development, at jboyle@primaryimmune.org or 443-632-2554.

Thank you!

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 (EST)

E-mail: development@primaryimmune.org

Mail: IDF, 110 West Road, Suite 300
Towson, MD 21204
For an Updated IDF Calendar of Events, Visit
www.primaryimmune.org/event-calendar.

Immune Deficiency Foundation
2015 NATIONAL CONFERENCE
New Orleans  June 25-27
Hyatt Regency
New Orleans
Registration begins
February 2015

Save the Date
More Details to Come

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