A team led by the Immune Deficiency Foundation (IDF) has been approved for a funding award by the Patient-Centered Outcomes Research Institute (PCORI) to develop and expand a health data network that will be part of PCORnet: the National Patient-Centered National Clinical Research Network. IDF’s PI CONNECT data network is one of 29 that were approved for a total of $93.5 million from PCORI on December 17, 2013 to form this new national resource that aims to boost the efficiency of health research.

PCORnet will join together networks operated by both patient communities and health systems and will require patients’ and other stakeholders’ involvement in all aspects of the collection and use of the data. By enabling researchers and patients, clinicians, and other end-users of study results to interact directly and jointly determine research priorities, such as the selection of specific studies to support, PCORnet aims to advance the shift in clinical research from investigator-driven to patient-centered studies.

During the next 18 months, the IDF-led team will use the PCORI funds to expand and improve its systems, work to standardize its data, and be part of the process to develop policies governing data sharing and security and protection of patient privacy. It also will refine its network’s capacity to engage and recruit patients and other stakeholders interested in participating in research.

The team is led by principal investigator Kathleen Sullivan, MD, PhD of Children’s Hospital of Philadelphia and member of the IDF Medical Advisory Committee.

“Currently, two unique data sets for primary immunodeficiency diseases (PI) exist: the IDF eHealthRecord, an electronic personal health record for patients with PI, and the United States Immunodeficiency Network (USIDNET) patient-consented registry, a data-validated registry of clinical information,” explained Dr. Sullivan, “For those patients who choose to participate, PI CONNECT will provide the opportunity to meld these two data sets to maximize the breadth of data on PI and accelerate understanding and treatment of these rare diseases.”

“We are pleased that PI CONNECT will be part of this exciting initiative to build the data structures needed to significantly enhance the speed and efficiency of patient-centered comparative effectiveness research,” said PCORI Executive Director Joe Selby. “The process to select the awardees was very competitive and the PI CONNECT team demonstrated it has the expertise, resources, and commitment to engaging patients and other stakeholders to be an excellent fit in PCORNet.”

PI CONNECT was selected through a review process in which patients, caregivers, and other stakeholders joined scientists to evaluate the proposals. Applications were assessed for the capacity of their network to collect complete, comprehensive clinical data, how well they will engage patients and other stakeholders, and their ability to maintain data security and patient privacy among other criteria.

“The Immune Deficiency Foundation recognizes the magnitude of this award from PCORI. It will build upon our existing, robust programs supported by a motivated patient community who want results,” said IDF President & Founder Marcia Boyle, “We look forward to implementing PI CONNECT, ultimately helping to improve the lives of those living with primary immunodeficiency.”

All awards are approved pending completion of a business and programmatic review by PCORI staff and issuance of a formal award contract.

Continued on next page
PI CONNECT:
What Is It and How Does It Affect Me?

Currently, IDF has two unique programs for the PI community that together will form PI CONNECT: the IDF eHealthRecord and the USIDNET patient registry. The IDF eHealthRecord is an electronic personal health record built specifically for patients living with PI, and USIDNET is a research consortium that includes a patient-consented registry of those diagnosed with PI. PI CONNECT will help connect these already established networks to develop additional features, helping the PI community track their healthcare and have a voice in research.

**Use the IDF eHealthRecord**

The first step to being involved with PI CONNECT is to simply create an IDF eHealthRecord account at www.idfehealthrecord.org and start entering your medical information. If you already have an IDF eHealthRecord account, you are ahead of the game. Patients and caregivers can use this online resource to manage health information all in one safe, secure place.

Over the next 18 months, IDF will develop several key features to enhance the IDF eHealthRecord and ultimately form PI CONNECT. These features include a mobile application, or app, that will make tracking and sharing your medical information more convenient. The app will use the built-in functionality of smartphones, in particular, the calendar integration and notifications that can be set for medication reminders. If you receive immunoglobulin therapy, you will be able to easily log your infusion right from your smartphone or tablet using the camera on your phone to scan the bottles’ barcodes.

**Register with USIDNET through PI CONNECT**

PI CONNECT will allow users to electronically consent from the IDF eHealthRecord directly to the USIDNET patient-consented registry. Patients will then have the option to safely and securely add their de-identified IDF eHealthRecord information to the USIDNET registry and be a part of PI CONNECT. Patients have a unique opportunity to have a voice in research through PI CONNECT by sharing outcomes and posing questions to researchers, and creating two-way communication between researchers and patients. Using de-identified data of patients with PI will help unify researchers and increase awareness of PI among them.

Overall, PI CONNECT is the next step in revolutionizing how the PI community tracks their healthcare and helps advance research with the ultimate goal of better understanding PI and improving health outcomes for all patients. Look for more information about PI CONNECT in the coming months.

**What You Can Do Now**

Create an IDF eHealthRecord account and start managing your health information: www.idfehealthrecord.org. Need help? IDF staff can provide answers to your questions and provide personalized assistance: info@idfehealthrecord.org or 800-296-4433.
Experience the “New” IDF Friends

IDF Friends has been completely redesigned and built on a new platform!

IDF Friends is a private social network and discussion forum designed only for patients and family members living with primary immunodeficiency (PI). The new network is mobile-responsive, ready for your tablet and smartphone use, and features a new user-friendly layout. Most importantly, the new site is 100% private and visible only to members—no one may access any site content without creating an account.

IDF Friends is a comfortable place for people to discuss issues and concerns that they might not discuss elsewhere, making the social network unique for that reason. It gives people affected by PI the opportunity to offer and receive peer support, ask questions, make suggestions, share their stories, and connect with others through words, pictures, and video.

The usernames, profile information, groups, discussion forum topics and posts from the old IDF Friends have been transferred over. You will be able to login to the new site with the same sign-in information you have always used for your IDF Friends account.

Once you login to the new site, there is a helpful “How to Get Started” guide and a “FAQs” page available for your reference while getting to know the new site. If you have specific questions, use the “Contact Us” page to get personalized assistance—we are happy to help!

We are confident that as you become more comfortable with the new IDF Friends you will find it to be a valuable resource for living with PI. We have heard from many users:

- “I’m really enjoying the new site! We are getting a lot of new posters, too, which is kind of interesting in and of itself!”
- “I am so glad forums like this exist and I want to thank those who make it possible!”

So come join the hundreds of members of IDF Friends and experience it for yourself.

Visit www.idffriends.org today!

Site Features

IDF Discussion Forums and Group Forums - The IDF Discussion Forum, the most popular feature, is a message board with sections created by IDF, where people can hold conversations, ask questions and post messages. There are also Group Forums, which are message boards under each user-created group.

Participating in Groups - Joining or creating a group allows you to share information about specific issues that can relate to everything from a particular PI disorder to a specific segment of the community. You can create groups to make announcements, join discussions, or even share pictures.

Profile Pages - Every user has a profile page, and you can access all of the following from your profile page: Messages, Friends, Groups, Gallery, Forums, Activity, Profile, and Settings.

Activity - On the homepage is a section called “Latest Activity.” This is a feed of activity such as status updates from users, new groups created, items added to galleries, new members to the site, members who have joined a group, and more.

Chat - IDF Friends now has a chat/instant messenger feature. You can invite multiple users to any chat.

Friends - Send friend requests to community members who share common interests, geographic location, etc.

Galleries - You can add photos and comment on individual pictures, and your comment will be added to the Activity Feed.

IDF Friends is made possible by unrestricted educational grants from Baxter International Inc., CSL Behring, Grifols and IgG America/ASD Healthcare/US Bioservices.

Learn More:

With EARLY DIAGNOSIS and PROPER TREATMENT, many with PI can live healthy, productive lives.
Denis Downton has been living with Common Variable Immune Deficiency (CVID) for 33 years. He was officially diagnosed in 2003 and experienced years of complications from CVID and other illnesses. He struggled for answers and correct treatments, encountering, as he describes, “a tragedy of errors and a slow and constant destruction upon my life.” On October 12, 2013, Denis finally found a supportive and accepting place where he belonged.

“I attended the Indianapolis IDF Education Meeting,” explains Denis, “This awarded me many wonderful experiences from PI education, support and acceptance from other patients, along with the learning of all that the IDF has to offer. I finally felt that true and complete feeling of belonging ... Home! Thank You IDF!!!”

Local Patient Education Meetings, like the one Denis attended in Indianapolis, are held across the country throughout the year. Created and organized by IDF with the help of local volunteers and healthcare professionals, the meetings are designed to provide individuals and family members with valuable information about the treatment and management of primary immunodeficiency from healthcare and life management experts. Exhibits provide the most current information on products and services related to PI. At the end of the meeting, patients and family members part in a “Person-to-Person Discussion” to share experiences and connect with others. Often, an IDF Patient Education Meeting is the first opportunity for a patient to meet another person living with primary immunodeficiency.

In 2013, IDF reached approximately 1,450 people through 20 Education Meetings, 5 Operation Outreach* meetings, and three Family Conference Days, which are Education Meetings with the addition of a youth program for ages 5 and up. More than 90 professionals donated their time and expertise by presenting at the meetings.

As a chronic, rare disease community, it is crucial to provide information and support to those living with primary immunodeficiency, like Denis. IDF Patient Education Meetings can truly make a world of difference, fostering a sense of belonging and creating a supportive and accepting place—a home for the primary immunodeficiency community.

There will be more Patient Education Meetings in 2014! Stay tuned—cities and dates will be posted on our event calendar throughout the year: www.primaryimmune.org/event-calendar. Follow the IDF blog for recaps of each meeting: www.primaryimmune.org/blog.

2014 IDF Patient Education Meetings are supported by charitable donations from Baxter International Inc., CSL Behring, Grifols, Biotest Pharmaceuticals, IgG America/ASD Healthcare/US Bioservices, Octapharma, Sigma-Tau Pharmaceuticals, CVS Caremark, Kedrion Biopharma, Vidara Therapeutics, Walgreens-IG Therapy Program.

*Operation Outreach meetings are solely supported by CSL Behring.
Learn — Connect — Be a Part of the IDF Community

IDF Retreats are weekend gatherings designed with everyone in the primary immunodeficiency community in mind—including you! Patients, parents, siblings, children and partners are encouraged to attend and learn how to develop better approaches to living with primary immunodeficiency. Plus, you can connect with others going through similar experiences and have some fun!

Learn from Experts
You will learn the latest information about the treatment and management of primary immunodeficiency diseases from leading physicians and healthcare professionals. You can get your questions answered about everyday concerns during panel discussions with experts in their fields. For the younger members of the community, the youth and teen programs offer both education and fun.

Connect with Others
Whether you are newly diagnosed or have been living with a primary immunodeficiency disease for years, IDF Retreats offers you an opportunity to connect with others. Enjoy an atmosphere where you can build relationships with others who share common experiences, therapies and feelings.

At the Retreats

Adults will
• Discover more about primary immunodeficiencies, your immune system, and immunological testing.
• Gain knowledge about therapies – immunoglobulin replacement, antibiotic and antifungal therapies, and bone marrow transplantation.
• Find out how to manage living with a chronic illness.
• Understand how to work with your health insurance provider.
• Share coping tips and ideas with your peers.
• Take advantage of the Ask the Expert sessions to get your questions answered.

Youth will
• Join an age specific group and enjoy age-appropriate activities presented by healthcare professionals, educators and IDF staff.
• Participate in a wide range of fun, interactive games and gatherings to learn about the immune system, gain life skills and understand PI.
• Attend sessions that will challenge and develop their creativity while learning how their lives can be healthy and fulfilling.
• Connect with other youth living with PI.
• Have a great time!

In Atlanta, there will be separate afternoon programming for the CGD community.

REGISTER ONLINE AT www.primaryimmune.org

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<th>Family - $195</th>
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<td>(5-8 persons, includes two hotel rooms)</td>
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Space is limited and will be assigned on a first-come, first-served basis so don’t delay!

Registration is all inclusive and covers your hotel room for 2 nights, meals (Friday dessert reception, Saturday breakfast, lunch and dinner, Sunday breakfast) and programming. For more information, please contact IDF at 800.296.4433 or retreats@primaryimmune.org.

The IDF Retreats are supported by charitable donations from Baxter International Inc., CSL Behring, Grifols, IgG America/ASD Healthcare/US Bioservices, Octapharma and Vidara Therapeutics.

Atlanta, GA
June 20-22, 2014
Marriott Atlanta Buckhead Hotel and Conference Center

Speakers
Rebecca Buckley, MD
Duke University School of Medicine
Mary Ellen Conley, MD
LeBonheur Children’s Hospital
Carla Duff, CPNP, MSN, CCRP
University of South Florida
Jennifer Leiding, MD
University of South Florida
Peter Mannon, MD
The University of Alabama - Birmingham
Donna Marie Meszaros, PhD
Abaris Behavioral Health and Apex Behavioral Health Western Wayne
Jennifer Shih, MD
Emory University Hospital
John Sleasman, MD
Duke University School of Medicine

Portland, OR
September 5-7, 2014
Embassy Suites Portland Downtown

Speakers
Michael Barrett, MD
Kaiser Permanente
Manish Butte, MD, PhD
Stanford University School of Medicine
Daniel DeMerell, MD, MPH
Asthma, Allergy & Dermatology Associates, P.C.
Robert Lawrence, MD
Kaiser Permanente
Hans Ochs, MD
University of Washington School of Medicine
Jennifer Puck, MD
University of California - San Francisco
Marc Riedl, MD, MS
University of California - San Diego
John Seymour, PhD, LMFT
Minnesota State University - Mankato
Suzanne Skoda-Smith, MD
University of Washington School of Medicine
M. Elizabeth Younger, CRNP, PhD
Johns Hopkins Hospital
April is National Primary Immunodeficiency Awareness Month! Join IDF, in partnership with World PI Week celebrated April 22 to 29, to promote awareness of primary immunodeficiency diseases (PI) in your community.

If you live with primary immunodeficiency or you have a significant relationship with someone who is affected, you know how important it is to raise awareness and understanding about these rare diseases. You have the power to educate and inform people about primary immunodeficiency, and this knowledge will lead to early diagnosis and appropriate treatment.

To get you started, below are ways you can help. Have fun, be creative and help increase awareness of primary immunodeficiency!

**Get the Word Out and Help Others**

**New “Learn More” Poster**

IDF programs and resources produce benefits for thousands of people living with PI, but people need to find IDF first! IDF developed a new awareness poster to lead patients and family members to IDF to use our services and innovative materials. Awareness Month is the perfect time to distribute it.

Start in your community! You can download or order awareness posters, information cards and IDF publications to distribute at libraries, doctor’s offices, infusion centers, home healthcare companies, places of worship, schools and other civic organizations. No matter how or where you decide to get your message across, IDF has the resources you need. Download materials at www.primaryimmune.org/awareness, or order copies by contacting IDF at info@primaryimmune.org or 800-296-4433.

**Use Social Media**

Use social media to share basic facts and information about primary immunodeficiency.

- Log into IDF Friends and connect with others living with primary immunodeficiency diseases in discussion forums and groups. Find others in your area to organize your efforts: www.idffriends.org.
- Teens can share what they are doing to promote awareness in IDF Common Ground, IDF’s social network just for teens: www.idfcommonground.org.
- Share your story with your own video at IDF Reel Stories: www.primaryimmune.org/idf-reel-stories.
- Like IDF on Facebook, follow @IDFCommunity on Twitter and Instagram and encourage your friends and followers to do the same! #primaryimmune #PlAwareness

**Contact Local Media**

Tell your story to the local media with the help of our Media Kit at www.primaryimmune.org/awareness. The kit includes steps on how to go about contacting the media, sample letters and press releases, FAQs about primary immunodeficiency diseases and other helpful information to use when reaching out to your local media. News outlets are always looking for a good human interest story, so contact them and share yours!

**Learn More:**

250,000 people have been diagnosed with PI in U.S., and thousands more go undetected.

April: National Primary Immunodeficiency Awareness Month!
Pay it Forward

Almost all of IDF’s services and materials are provided completely free of charge, and so IDF’s ability to serve the PI community depends on the philanthropic support of people like you. If you have been helped by IDF in the past, will you consider “paying it forward” and ensure that the next person who seeks out IDF receives even more help and support?

If you have not made a gift to IDF before (or if you have not given recently), please consider making a $25 gift during Awareness Month so you can be counted as one of the people who help keep IDF strong. You can use the enclosed envelope to send in your donation, or give online at www.primaryimmune.org/PayItForward.

We are grateful to all of our donors for helping us serve the PI community. If you have questions about giving to IDF, contact us at 800-296-4433 or development@primaryimmune.org.

Take Action and Advocate

Advocacy gives you a voice! You do not need to be a professional lobbyist to influence how policy and legislation is created. Grassroots advocacy helps to personalize an issue and begins to help solve some of the problems that our community faces. Visit the IDF Advocacy Center to view priorities for our community. Be sure to sign up for IDF Action Alerts and get your IDF Advocacy Toolkit at www.primaryimmune.org/idf-advocacy-center.

World PI Week: April 22-29

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

Tell Us What You Did

Make sure you tell us what you did to promote awareness in your community! Submit your stories and pictures for inclusion in the IDF Blog and/or the IDF ADVOCATE newsletter: idf@primaryimmune.org.

If you have questions, contact IDF at 800-296-4433 or e-mail idf@primaryimmune.org. Thank you for promoting awareness!

And Don’t Forget to THINK ZEBRA and Wear Zebra!

In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras,” and are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra. Patients with primary immunodeficiency diseases are the zebras of the medical world. So the IDF says THINK ZEBRA! This April wear your favorite zebra attire and post your photos to IDF Friends, Facebook, Twitter or Instagram!
What is a sinus infection?
A sinus infection, or acute sinusitis, is an inflammation of one or more of the sinuses. The sinuses are small cavities, lined with mucous membranes, located in the facial bones surrounding the nasal cavities. The basic causes of sinusitis are the blockage of normal routes of sinus drainage and infections spread from the nasal passages. Pain, particularly in the forehead and cheekbones, and tenderness over the face in these same areas are characteristic symptoms. In addition, there may be pain in and around the eyes and in the teeth of the upper jaw. The pain and headache associated with sinusitis is typically more pronounced in the morning due to accumulated secretions in the sinuses during sleep. Being in an upright position during the day facilitates sinus drainage and usually provides some temporary relief. Depending on the amount of sinus drainage, there may be cough, throat irritation, bad breath and decreased appetite. Sinusitis may be accompanied by a fever.

A sinus infection can be difficult to treat in the patient with a primary immunodeficiency and may require a longer course of antibiotics than would be usually prescribed. Many patients get benefit from the use of daily sinus rinses to keep the sinuses free of accumulating secretions. Repeated or prolonged episodes of acute sinusitis may lead to chronic sinusitis and damage to the mucosal surfaces.

1) How safe are sinus rinses?
Many healthcare providers believe that sinus rinses may help prevent infections. As mentioned before, the sinuses are small holes in your facial bones. It is easy for mucus to get stuck in them and serve as a sticky surface for bacteria and other disease causing organisms. Sinus rinses may help to clear the sinuses of this mucus. If your provider recommends a sinus rinse, like a Neti-pot or similar device, make sure that you follow the instructions carefully for cleaning it and keeping it free of contamination. There can be contamination in the rinse device or the water. Therefore, it is recommended to clean the rinse bottle and use sterile water in rinses because tap water or well water may be more risky.

2) Does the color of nasal secretions or mucus I am coughing up have any significance?
Technically, the color of mucus does not mean you have an infection. You can have an infection with mucus of any color—clear, yellow, green or anything in between. Mucus is part of your body's defenses and can be a response to any kind of irritation. All the symptoms count, not just the color of the mucus. If you have a lot of mucus, if it is usually clear and changes color, if you have a fever, fatigue, headache, or pain over your sinuses—these are all signs that you might have an infection, so you should report these to the appropriate member of your healthcare team.

3) I receive immunoglobulin replacement therapy—why do I still get sinus infections?
While the goal of immunoglobulin replacement therapy is to prevent infections, it is not going to prevent every infection. If it has taken a long time to get to a diagnosis, like many with Common Variable Immunodeficiency, the patient may have had chronic sinus infections for years and may have had sinus surgery or surgeries. There may already be some damage to the mucosal lining of the sinuses which may increase sinus infections. In addition, Ig replacement does not include IgA, which is effective in treating the mucosal lining.

4) Is sinus surgery more dangerous in patients with a primary immunodeficiency since they don’t fight infections well?
This is a conversation to have with your immunologist and surgeon. All surgical procedures pose a risk. However, if you are compliant with your immunoglobulin replacement therapy and prophylactic antibiotics (if they are prescribed) and you are in good health at the time of surgery, your risks are roughly the same as a person without an immunodeficiency. It is important to know that sinus surgery is not a guarantee against future infections. All surgical interventions need a risk/benefit analysis between you and your healthcare providers.

5) If you are a patient with PI who has a fever for three days and had typical sinus infection symptoms, who should you see? Primary care provider, otolaryngologist or immunologist?
This depends completely on the arrangements you have made with your healthcare providers. A good rule of thumb is to start with your primary care provider (PCP). Your immunologist is usually a specialty care provider and may not be able to see you urgently. Your PCP can always consult with your immunologist if they have questions about management or treatment. The important thing is to make sure that each of the members of your healthcare team have clearly defined roles and that you understand what these roles are and there is a plan in place if you get sick.

6) To drain my sinuses, would it help to stand on my head once or twice a day?
Actually, this would work against you because gravity is key to draining your sinuses. Think about how congested you are when you wake up in the morning after sleeping horizontally and how that congestion dissipates when you are upright (and after you have breathed in the steam from your shower). Make sure you communicate with your healthcare provider about your symptoms and what can be done to relieve them.

In all cases, if you have a sinus infection, please first consult your healthcare provider. For additional information about common infections as well as general care, use the IDF Patient & Family Handbook for Primary Immunodeficiency Diseases. To order a copy or download a PDF, go to www.primaryimmune.org/idf-publications/patient-family-handbook.
IPOPI Hosts
1st International Primary Immunodeficiencies Congress in Portugal

IPOPI, the International Patient Organisation for Primary Immunodeficiencies, organized the 1st International Primary Immunodeficiencies Congress (IPIC) held in Estoril (Lisbon), Portugal November 7-8, 2013. The congress provided a unique, multi-disciplinary international forum focusing on clinical care developments in the field of primary immunodeficiency diseases. Over 400 participants from around the world attended, including patient group leaders, physicians, nurses, industry representatives and others.

The congress featured world renowned clinical and scientific experts who presented about primary immunodeficiency treatments, complications management, genetic studies and counselling, primary immunodeficiency pathogenesis and more. IDF President & Founder Marcia Boyle, who serves as a member of the IPOPI Board, participated in an informative presentation on SCID newborn screening, presenting the latest developments in the U.S.

“When we first started to discuss the concept of IPIC, we wanted to make sure that we would create an international congress on primary immunodeficiencies that would be appealing to all stakeholders and would complement other existing international and regional events such as the ESID congresses,” explained IPOPI President Johan Prevot, “IPOPI is delighted that our first congress was so successful, and we very much look forward to organizing the second edition in Budapest, Hungary in 2015.”

For more information about IPOPI and IPIC, visit www.ipopi.org.

**States currently screening for SCID:**
- California
- Colorado
- Connecticut
- Delaware
- Florida
- Iowa
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- New York
- Ohio
- Pennsylvania
- Texas
- Utah
- Washington
- Wisconsin
- Wyoming

**States currently planning to begin screening in 2014:**
- Illinois
- Maine
- Missouri
- Nebraska
- North Dakota
- Oklahoma
- Oregon
- Puerto Rico
- Rhode Island
- South Carolina
- South Dakota
- West Virginia

**States where Advisory Committees have approved adding SCID, but have a longer timetable for implementation:**
- District of Columbia
- Georgia
- Maryland
- North Carolina
- New Jersey
- Virginia

**Territories screening:** Navajo Nation
Medicare IVIG Demonstration Project Update

The Medicare IVIG Access Act that was signed into law in January 2013 instructed the Centers for Medicare and Medicaid Services (CMS) to create a three-year demonstration project that would reimburse for the items and services needed to do home infusions of IVIG for patients on Medicare. Prior to this demonstration project, the items and services were not reimbursed by Medicare and only the cost of the immunoglobulin itself was paid for by Medicare. As the law was written, and as IDF has reported, the demonstration project was meant to begin in January 2014. CMS has announced that the demonstration project would not begin in January 2014 as anticipated, as there are numerous system changes and approval processes still needed to implement the project. CMS plans to start taking applications later in 2014 and begin delivering services after an enrollment period of about one month.

IDF is continuing its meetings and discussions with CMS about implementation, and although everyone is disappointed about the delay, all involved understand that it is important for this demonstration project to be executed correctly. Although there is no new anticipated start date, it is likely that the demonstration project will be live sometime in the latter part of 2014.

If you would like to be a part of the Medicare IVIG Demonstration Project and want to receive updates from IDF, e-mail idf@primaryimmune.org or call 800-296-4433. We will contact you when we know more about the updated timeline and enrollment procedure.

IDF Walk Expands in 2014

The strong momentum of IDF Walk for Primary Immunodeficiency continues into 2014—we are expanding from three to six cities!

2014 Locations
- Philadelphia, Penn's Landing September 28
- Boston, Boston Common October 5
- Los Angeles, Griffith Park October 19
- Greater Chicago, Cantigny Park (Wheaton) October 26
- New York City, Foley Square/Brooklyn Bridge October 26
- Houston, Discovery Green November 9

The inaugural year was a huge success. We raised a grand total of $430,000. We look forward to making IDF Walk for Primary Immunodeficiency bigger and better in 2014, and we can with your help!

Get Involved
- **Like Us** - Join us on our new, official IDF Walk for Primary Immunodeficiency Facebook page: www.facebook.com/WalkforPI. Get updates about all of the walks, share your fundraising progress, and post photos.
- **Create a Team** - Go to www.walkforPI.org and get your team started. It’s easy to set up and even easier to track your progress and keep the fundraising going.
- **Volunteer** - In each city, we are gathering volunteers and always looking for more help. Contact IDF at walk@primaryimmune.org.

We hope to see you in one of the six cities in 2014!

Virtual Walks
If you do not live near one of our six sites for 2014, you can still participate. You can be a Virtual Walker and organize 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 you’ll be eligible for the same incentive prizes. The only real difference is that neither you nor the people you recruit will have to get up early on a weekend morning! For more information on our virtual walk program, please visit, www.walkforPI.org.

We thank our 2014 National Sponsors for their continued support.

National Presenting Sponsor
- Baxter International Inc.

National Supporting Sponsors
- Grifols
- IgG America/ASD Healthcare/US Bioservices
- Vidara Therapeutics

www.walkforPI.org
The IDF Legacy Society recognizes those who have included IDF in their wills or who have created other types of planned/legacy gifts in support of IDF. This type of giving makes a lasting impact by helping future generations of individuals living with primary immunodeficiency.

If you have chosen to include IDF in your financial or estate plans, please contact us and become a member of the IDF Legacy Society. Membership involves no dues, obligations or solicitations, but it does allow us to thank and recognize you for the future plans you have made and it may inspire generosity in others. Each Legacy Society member will enjoy benefits including personal updates from IDF’s President as well as recognition in publications and at special events.

For more information about the IDF Legacy Society, contact John Boyle, Director of Development, at jboyle@primaryimmune.org or 800-296-4433.
For an Updated IDF Calendar of Events, Visit www.primaryimmune.org/event-calendar.

IMMUNE DEFICIENCY FOUNDATION RETREATS 2014

Atlanta, GA
June 20-22, 2014
Marriott Atlanta Buckhead Hotel and Conference Center

Separate afternoon programming for the CGD community in Atlanta.

Portland, OR
September 5-7, 2014
Embassy Suites Portland Downtown

Register now!
Read more about IDF Retreats on page 5.

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#idfretreats