Volunteer Kathi Beiswenger brings educational materials from the Immune Deficiency Foundation (IDF) everywhere she goes. “Every time I visit a new doctor, the emergency room, outpatient clinic, surgical suite, inpatient hospital, dentist, nursing school, etc. I bring materials,” she explains. “I carry IDF materials in my car. You never know when you may run into someone to share the information.”

Kathi, a nurse, mother of two and grandmother of four, believes that it’s absolutely critical to create awareness among healthcare professionals because they are in the unique position of being able to identify primary immunodeficiency diseases (PI) and diagnose individuals early to prevent permanent damage and to make their lives more comfortable and productive. She also knows how helpful her connection with IDF has been and wants all people with PI to have the same opportunity.

After constantly suffering from infections for years, Kathi was finally diagnosed with PI in 2003. Soon after, she started her search for information and for others with PI. “Like many patients I felt very alone with my disease. My doctors had never heard of it,” she says. “IDF became a lifeline for me. I found education, resources, support, and contact with others with PI.”

Kathi’s regular distribution of IDF materials—reaching more than 50 medical offices or centers over the past few years—has paid off. She learned that four patients were diagnosed at a primary care provider’s office after she brought IDF publications for the staff there. A friend, who is a nurse at another practice, said that a pediatrician diagnosed two children after Kathi left IDF materials in the office.

Kathi is not alone in her efforts, but IDF needs more volunteers like her. Every day we hear from individuals living with PI who are searching for information and looking to meet others going through similar experiences. Information can be difficult to find, and members of the PI community often feel alone in their struggle. IDF is well known for its publications and programs developed by experts that provide education and empowerment to so many. The hurdle the Foundation faces, however, is getting IDF resources into the hands of those who need them the most—people living with PI.

Volunteers can serve the PI community through the IDF Outreach Initiative, a new project to engage the community. Volunteers can serve as an IDF Liaison and build relationships with healthcare professionals.

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IDF Outreach Initiative

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IDF Liaisons

IDF Liaisons are trained to specifically connect and build relationships with clinicians who care for individuals diagnosed with PI, as well as with other providers who are likely to see these patients. Liaisons explain IDF and all it has to offer, and encourage them to share IDF information with their patients. Liaisons keep them apprised of new IDF programs and materials, and ensure they have an inventory of supplies to distribute. They may also contact local medical associations to present information about IDF resources for healthcare professionals.

Volunteer Training and Support

IDF staff members work together with IDF Liaisons to prepare them to be successful in their activities. IDF provides an orientation, training, prepared materials, administrative support, guidance and encouragement every step of the way.

IDF encourages those interested in helping with this new initiative to contact IDF. This volunteer opportunity is perfect for motivated individuals who want to make a difference for others living with PI. IDF needs volunteers who understand the importance of education, understanding and encouragement in helping individuals live a fulfilling life with PI.

Kathi recommends that volunteers reaching out to healthcare professionals be friendly, smile and speak with any staff you meet. She views it as planting the seed of awareness for medical staff, who may remember what you have shared in the future. “I share the THINK ZEBRA! metaphor and how long it takes for the average patient to be diagnosed,” she says. “With this new liaison program, I hope more and more people will THINK ZEBRA!” And she does suggest carrying IDF materials in your car, just in case.

Kathi with her grandchildren (from left) Noah, Emma, Hannah, Josh, and her husband Bill.

IDF Get Connected Leaders

Another important component of the IDF Outreach initiative is IDF Get Connected Groups. Sometimes individuals and family members simply want to talk with someone who understands what it’s like to live with PI. They find value in actually meeting others in person, learning the latest about PI and connecting about much more than their diagnosis. The IDF Outreach Initiative encourages individuals living with PI to get together in their local areas through IDF Get Connected Groups.

Volunteers acting as IDF Get Connected Leaders plan, organize and attend the gatherings. These groups are in-person networking opportunities designed to bring together individuals from the PI community in their local area. IDF Get Connected Leaders facilitate a welcoming environment conducive to sharing ideas and support, so that participants feel a sense of belonging to the IDF community, assuring them that they are not alone.

A Get Connected Group in Amarillo, TX met for the first time on September 12, 2015. IDF Get Connected Leader Amy Gilbert organized the meeting.

Become an IDF Liaison or IDF Get Connected Leader

Contact IDF at 800-296-4433 or volunteer@primaryimmune.org.

Learn more about the IDF Outreach Initiative at www.primaryimmune.org/volunteer

The IDF Outreach Initiative is sponsored by Baxalta US Inc.
In 2010, at the age of 24, Andrea Wszelaki was diagnosed with Common Variable Immune Deficiency (CVID), a type of primary immunodeficiency disease (PI). She had suffered from debilitating, chronic infections since she was 18 months old. “I was ill much of my life, and so ill in my early 20s that I had to stop going to college,” she recalls. After she was finally diagnosed and started receiving immunoglobulin (Ig) replacement therapy, her health improved tremendously. “Immunoglobulin infusions changed my entire life,” Andrea explains.

Everything was going well until the spring of 2014 when Andrea received a letter from her insurer telling her that she would have to go off her infusions for six months to demonstrate that she needed them. “The situation was a desperate one, not only because my health was at stake but also because my husband and I had just found out I was pregnant with my daughter,” she says. “The insurer was not only taking my lifeline but my baby’s too.”

Andrea’s insurance company had implemented a new policy aimed at finding people who had been misdiagnosed and who really did not need Ig therapy. However, the policy would have forced her and others like her to go without the therapy that made a healthier and independent life possible. She says, “I was completely overwhelmed, terrified and desperate to quickly resolve the issue.” After weeks of pleading phone calls with the insurance company, Andrea contacted IDF.

IDF had been alerted about various insurers who had recently implemented similar policy changes, and the Foundation worked with expert immunologists to recommend more medically appropriate policies for insurers to use. Fortunately, IDF had already convinced Andrea’s insurer to modify their Ig policies, but the change in policy clearly had not been communicated throughout the insurance company.

IDF explained to her insurer that withholding Ig replacement therapy for months to find a few individuals who may have been misdiagnosed jeopardizes the health of those with PI. It is also unlikely to save money as usage of emergency and hospital services will increase and permanent disability is likely.

Andrea remembers, “The insurer called back to say that the letter shouldn’t have been sent to me, given their new policy, and allowed me to continue therapy.”

Unfortunately, there are many others who are dealing with similar situations with their insurers—having to fight new restrictive Ig policies. Some policies created by health insurance companies force patients stabilized on a specific Ig product to stop or delay treatment, resulting in dangerously low blood serum levels. They may even be asked to switch to a new Ig product, get retested and/or change the location or method of infusion.

Mark Ballow, MD, a member of the IDF Medical Advisory Committee and former President of American Academy of Allergy, Asthma and Immunology, states, “I’ve seen firsthand the advantages for payers when they work with medical experts and foundations before changing policies that restrict treatment options. I’ve also seen how failing to get this input, especially when high-risk patient populations are involved, hurts both patients and insurers.”

Andrea and her family are doing well, and her treatments continue to make a huge difference in her health. Helping people like Andrea is why IDF partners with some health insurers to develop policies that cover proper treatments for patients with PI while saving costs. The end result is a win-win for both patients and insurers.

*If you have PI and have an issue with your health insurer that could be harmful to your health, contact IDF at 800-296-4433 or info@primaryimmune.org.*
When someone is first diagnosed with a primary immunodeficiency disease (PI), the search for information begins. Often individuals have questions about what research is being done and want to know how they can get involved. The Immune Deficiency Foundation (IDF) has continued to help advance research over the years by focusing on the patient’s experiences and the data they can provide to better understand these rare disorders. Earlier this year, IDF launched the PI CONNECT Research Forum to help power research and take part in the research conversation. Patients can consent into PI CONNECT through IDF ePHR, the online personal health record for patients with PI.

"Taking part in the PI CONNECT Research Forum interested me because it gave me the chance to interact with people who are going through the same struggle as I am," explains James Severin who was diagnosed with PI three years ago and currently serves as an Online Forum Moderator/Fellow for the PI CONNECT Research Forum. "Often I felt alone in my fight and at a loss for answers, isolated by my situation and others’ lack of knowledge or understanding. Participating in the forum gives me a small role in being able to help an organization that I believe is doing a ton of good for people with PI."

The forum is a part of PI CONNECT, the IDF Patient-Powered Research Network, which joins the information patients enter into IDF ePHR with clinical data from the United States Immunodeficiency Network (USIDNET) patient consented registry. Members of PI CONNECT have access to the forum where they can propose and discuss research questions, and attend live, interactive webinars given by distinguished researchers. The patient voice holds great promise to provide researchers further understanding about the diagnosis and treatment of PI.

"I always find the research articles that either the IDF researchers or community members post interesting, as they not only lead to interesting discussions but also keep everyone up to date on what exactly the challenges are in fighting PI," says James.

Lively discussions in the forum have included a wide range of topics. Users have discussed the challenges of getting an actual diagnosis of PI and separating that diagnosis from any other complication, such as an autoimmune disease or other co-morbidity. Patients have also discussed their own experiences, and researchers help parse through their issues.

"We are fortunate to have these exceptional researchers participating in the forum," Marcia Boyle, IDF President & Founder, says. "PI CONNECT empowers patients to participate and help transform research by sharing their data and their individual experiences."

James explains, "Working in the forum, not only exposes me to other patients and their concerns, but also has helped demonstrate how researchers use their knowledge and data to provide as much insight as they can in the forum environment."

Due to his experience with PI, his new goal in life is to attend medical school and become a physician, so that he can help other people with PI.

Three years after diagnosis, James is still working towards getting his health fully on track. He believes the PI CONNECT Research Forum lets people know that they are not alone and while the answers are not simple or quick, there are at least people out there working with patients to improve the fight against PI.

Join more than 1,200 individuals in PI CONNECT!

Go to www.IDFePHR.org, and create an account. During registration, you have the choice to consent into PI CONNECT. Once consented, you will receive access to the forum.
Choosing a Medicare Plan

There are so many options when it comes to Medicare coverage that individuals with primary immunodeficiency diseases will have to do a little investigative work to determine what will work best for them.

Immunoglobulin therapy, whether it be intravenous (IVIG) or subcutaneous (SCIG), is covered under the traditional Medicare Part B medical benefit. This is only covered at 80%, so individuals will want to look into getting a supplemental or medigap plan to cover the remaining amount.

If you don’t choose the traditional Medicare Part B medical benefit, you can choose a Medicare Advantage Plan (Part C). These plans are sold as an “all in one policy” and act more like a private insurance. According to Medicare regulations, the managed care plans must provide enrollees with all Part A and Part B benefits. Medicare Advantage Plans are not required to provide enrollees the same access to providers that is provided under original Medicare.

The cost for treatment is dependent upon the plan design. Individuals could have a flat $20 copay or could be responsible for a percentage of the cost (co-insurance). Over the past few years, patients with Medicare Advantage Plans have reported to IDF that most have a 20 to 30% coinsurance for treatment.

Unfortunately most of these patients picked the Medicare Advantage Plan thinking it acted the same as traditional Medicare Part B and a secondary plan. But, it is important to note that if individuals choose an Advantage Plan they are not eligible to obtain a secondary or medigap policy. So if you have an Advantage Plan, you cannot obtain a secondary or medigap policy, and for example, if you have a large co-insurance, you will be responsible for that co-insurance. Knowing the coverage before enrolling is essential.

State Differences

Since Medicare plans vary from state to state and even by counties within a state, individuals need to research for which plans they are eligible. Contact the state’s State Health Insurance Assistance Program (SHIP) as they have trained counselors who can explain what plans an individual is eligible for and assist in finding the answers to questions regarding coverage. To find a state’s SHIP program contact information, go to: www.bitly.com/SHIPprograms

Do a thorough plan comparison to determine what will work best. Information to know before purchasing a plan:

• What is my out-of-pocket maximum?
• Do I have a deductible?
• Is my deductible included in the out-of-pocket maximum or is it in addition to the maximum?
• How is immunoglobulin therapy covered?
• Do I have a coinsurance or a flat co-pay?
• Do I have options for site of care?
• Are there out-of-network benefits?

With the details of all plan options, an individual can make an informed decision on what will work best. Download the IDF Health Insurance Toolkit as it has helpful information and comparison worksheets.

www.primaryimmune.org/insurance-toolkit

Questions? Contact IDF at 800-296-4433 or info@primaryimmune.org.

Medicare IVIG Demonstration Project

Enrollment for the Medicare IVIG Demonstration Project is still open! New applications 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.

The IDF Consulting Immunologist Program provides physicians the opportunity to consult with expert clinical immunologists about patient specific questions and obtain valuable diagnostic, treatment and disease management information. Physicians can give patients the benefit of a second medical opinion on primary immunodeficiency diseases from a national network of renowned immunologists. Patients: This program is for physicians only. You may want to share information about the program with your physician.

For more information or to submit a request for a consult, go to: www.primaryimmune.org/consult

The IDF Consulting Immunologist Program is supported by charitable donations from AbbVie, Baxalta US Inc., CSL Behring, Grifols, Biotest Pharmaceuticals, IgG America | ASD Healthcare | US Bioservices, and Octapharma.
In 1980, the Immune Deficiency Foundation (IDF) was founded to provide individuals and families living with primary immunodeficiency diseases (PI) vital information and resources at a time when there were no patient organizations advocating for the PI community.

For 35 years, IDF has continued to help those searching for information and has become the voice of the PI community. Thanks to the support of generous donors, IDF has been able to reach more and more individuals and families with the Foundation’s world renowned publications and innovative programs.

The impact of IDF increases each year.

For example, last year:

• More than 13,000 patients and healthcare professionals attended nearly 180 educational presentations in 134 cities in 37 states.

• IDF’s patient advocacy services helped fulfill 6,500 requests from individuals and families seeking education, information and assistance.

• 140 teens participated in the IDF Teen Program, and 173 parents and teens attended IDF Teen Escape weekends.

• Peer Support Volunteers offer personalized encouragement and advice to more than 500 individuals and family members.

• Over 1,200 individuals and caregivers tracked and easily updated their health information with IDF ePHR, the electronic personal health record developed for people living with PI.

• The IDF website, the first place the PI community turns for information, received more than 60,000 sessions (visits) a month.

In honor of IDF’s 35th Anniversary, IDF encourages you to support our efforts by making a gift of:

$35
$350
$1,350
$3,500...

... or whatever amount you choose by December 31. Your anniversary gift will help us to ensure that IDF has the resources necessary as we prepare for the next 35 years.

Your contribution to IDF is more critical than ever in order to help us in our mission to support patients and families.

Simply complete and return the enclosed envelope, or donate online at:

www.primaryimmune.org/appeal

Thank you!
The 2015 IDF Walk for Primary Immunodeficiency season started off with a bang, and the fundraising continues! More and more members of the PI community are getting their friends and families involved, and raising funds for IDF. This year, IDF added an additional three walks in Cleveland, Fort Lauderdale and Minneapolis joining the existing sites of Boston, Chicago, Houston, Los Angeles, New York City and Philadelphia. Community walks were held in Charlotte, NC and Omaha, NE.

We are excited to announce that in 2016 IDF will add national walk sites in the following cities:

- Atlanta
- Charlotte, NC
- St. Louis

Registration will open in the spring.

Even though the actual walking is over, individuals and teams can continue to fundraise until December 31 for the 2015 walk season. There is even time to create a virtual walk team. No matter which walk, participants can still earn a t-shirt for raising $100. If you raise even more, you can earn other fantastic prizes!

The efforts and generosity of walk participants are making a huge difference. Recently, the IDF Board of Trustees voted to establish a research fund that will fund clinical, translational research projects aimed at directly impacting people with PI. The $250,000 allocated to this fund was made possible directly as a result of the funds raised through the 2014 walks. IDF will now be able to fund research in ways that it never has before.

Keep the Walk for PI momentum going and raise funds until December 31!

www.walkforPI.org

Thank You
2015 IDF Walk for Primary Immunodeficiency Sponsors!

National Presenting Sponsor
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IgG America | ASD Healthcare | US Bioservices
Option Care

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Have you ever wanted to share your story in a video? The Immune Deficiency Foundation (IDF) wants to hear from you! Your video can be a part of IDF Reel Stories, videos designed to encourage and empower fellow patients and their loved ones affected by primary immunodeficiency (PI).

There are more than 100 video testimonials that speak to the PI community on some level—whether as individuals, families or as members of the IDF community. The videos cover a wide array of issues and topics, and can be searched by status, patient life stage, messages, disorders, and treatment options.

We want to hear from you!

To learn how to submit your video, visit www.primaryimmune.org/idf-reel-stories.

IDF Reel Stories is sponsored by CSL Behring.
What You Need to Know about the “Cadillac Tax”

As part of the Affordable Care Act of 2010, an annual 40% excise tax on “high-priced” employer-sponsored health insurance plans will begin in 2018. This was instituted with the goal to help improve savings and reduce costs within the U.S. healthcare system. By discouraging higher value plans, in theory, patients would be more selective when utilizing the healthcare system. The drafters of this legislation assumed, at the time it was passed, that this tax would affect only very high-priced “Cadillac” or “luxury” employer sponsored healthcare plans. Unfortunately, this is forcing many employers to explore ways to avoid the tax by lowering the cost of their health plans, and many are already shifting costs to their employees in the form of higher deductibles, co-payments and out-of-pocket maximums. Despite common belief, these practices will affect far more than just luxury plans and have a devastating impact on those with severe chronic diseases, such as individuals with primary immunodeficiency diseases (PI), who depend on specialty and often costly medications to stay healthy. As employers and health plans transfer more costs to patients, individuals with PI face incredible out-of-pocket expenses that can even cost more than their mortgage, forcing some to go without treatment because they simply can’t afford it. The Cadillac Tax increases the likelihood that the most vulnerable in our country will forego care.

IDF urges the PI community to register for IDF Action Alerts so that they can be prepared to have their voice heard about this critical issue and the possible implications this tax imposes to people with PI.

Register for IDF Action Alerts!
www.primaryimmune.org/action-alerts

SCID Newborn Screening Expands

The IDF SCID Newborn Screening Campaign works to establish newborn screening programs for Severe Combined Immune Deficiency (SCID) in all 50 states. Dedicated IDF volunteers across the country have worked with IDF’s robust advocacy efforts and are making a tremendous impact. As of November 1, 2015, 34 states are screening for SCID, covering 75% of all births in the U.S.

In 2015, the following states began screening:
- Arkansas
- Hawaii
- New Hampshire
- Oklahoma
- South Carolina
- South Dakota
- Virginia

Six additional states have implementation plans in place to begin screening within the year, including Alaska, Georgia, Idaho, Kentucky, Maryland, Nevada, North Carolina, Tennessee and Vermont.

To stay updated, follow the IDF SCID Newborn Screening Blog: www.idfscidnewbornscreening.org

The IDF SCID Newborn Screening blog is sponsored in part by PerkinElmer and Sigma-Tau Pharmaceuticals, Inc.
Brush and Floss for a Sparkling Smile & Good Health

Your dentist recommends to brush and floss regularly, and it’s so important that you do! People with primary immunodeficiency diseases (PI), such as X-linked agammaglobulinemia, are prone to oral bacterial infections due to a lack of all immunoglobulins, including IgA. Most specifically IgA protects the mucosal surfaces, but IgG and IgM also play a part in the immune defense of the oral cavity. These bacterial infections (such as staph abscesses), viral infections (such as herpes simplex) and oral fungal infections can lead to a higher incidence of gingivitis, gum disease, periodontitis (decayed, missing and filled teeth) and dry mouth syndrome.

As such, individuals with PI should be closely monitored and treated by their dentist and dental hygienist to maintain good periodontal health. Good dental hygiene should be practiced, and regular dental checkups should be scheduled. Patients should brush and floss daily, use antiseptic mouthwash, eat healthy foods and limit sweets.

So don’t forget to take care of that smile for good health!

Have a question about living with PI? Ask IDF! • www.primaryimmune.org/ask-IDF • 800-296-4433
Each year leading companies in the healthcare industry provide philanthropic support to Immune Deficiency Foundation (IDF). Without such funding, IDF would be unable to provide our community with many of the services, resources and programs that contribute to the improved quality of life for the individuals and families of those living with primary immunodeficiency diseases.

IDF Core Service Sponsors are dedicated partners that support IDF at the highest level. They help fund direct services that offer peer support, help locate a specialist and offer information on dealing with health insurance issues. Local IDF patient meetings are offered throughout the country because of their generosity. They support medical and scientific programs like the IDF Consulting Immunologist Program and the IDF & USIDNET LeBien Visiting Professor Program, as well as IDF exhibits at medical meetings.

Funding from sponsors allows IDF to provide services and publications free of charge to our community.

Our sponsors understand the chronic nature of primary immunodeficiency. Because the diseases never go away, individuals and their families will continually rely on IDF, and the Foundation extends sincere appreciation to these companies for their continual support to make this possible.

**IDF Core Service Leaders**
- AbbVie
- Baxalta US Inc.
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- Accredo Healthcare
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- BioRx
- Ethical Factor Rx
- Matrix Health Group
- Orsini Healthcare
- RMS Medical Products

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

**Remembering Members of Our Community**

To remember members of the IDF community who have passed away, the Immune Deficiency Foundation has created a perpetual plaque. Individuals with PI, parents, medical professionals and caregivers can be honored through inclusion on this plaque. It is a tribute to memorialize those who were an important 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.

**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.
For an Updated IDF Calendar of Events, Visit
www.primaryimmune.org/event-calendar.