IDF Fights for Access to Care

Are your co-payments increasing? Are you facing denials from your insurance company? Is something standing in the way of your access to care?

You are not alone. Each year many people with primary immunodeficiency diseases (PI) struggle to receive their necessary treatments, as well as the services and supplies that make those treatments possible. Significant progress has been made in the treatment of PI, but these treatments often come at a financial burden and it is especially exasperating when health insurance companies deny coverage based on faulty guidelines. The Immune Deficiency Foundation (IDF) works to ensure the PI community receives the care and treatment they deserve.

Listening to the Individual
Recently IDF heard from patients who were denied immunoglobulin (Ig) therapy from some insurers. Working with the expert immunologists from the IDF Medical Advisory Committee, IDF submitted recommendations for changes to the companies’ Ig coverage policies to align them with the standards of care established by the American Academy of Allergy, Asthma and Immunology. IDF worked collaboratively with the insurance companies to change their policies to ensure that people with PI receive the therapy that best meets their medical needs as prescribed by a physician. IDF discovered this situation because patients contacted IDF for help. If we don’t hear from the community, we often won’t know what issues are the most important and what needs immediate attention. Your involvement is vital!

We encourage individuals with PI to contact us if they are denied access to care. We hear from people who face all kinds of insurance problems, including denials for therapy, procedures related to PI, reimbursement complications and help getting insurance. We respond on an individual basis to listen, to evaluate what’s happening and to either recommend resources, or, if possible, intervene on the patient’s behalf. IDF is here to help individuals navigate through the unique issues faced by the PI community.

Voicing Concerns to Policymakers
Our robust public policy program focuses on national, state, and local healthcare issues, serving as the leading voice for the PI community. During the past year, we developed and strengthened relationships with Members of Congress, hosted a successful Advocacy Day on Capitol Hill, and met with and provided policy comments to government officials to increase awareness of critical PI issues. As more insurance companies attempt to manage and even curb the use of Ig therapy, IDF has placed increased emphasis on state legislative and insurance issues, making access to quality care a top priority. This includes access to all treatments, all sites of care, and all specialists. The PI community has unique needs that are unfamiliar to most policymakers, so the Foundation is working to educate lawmakers and payers about these needs and the critical importance of life-long, life-saving therapies.

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IDF Fights for Access to Care

IDF continues to reach out to payers on a host of issues including appropriate Ig guidelines, sites of care and access to specialists. We regularly collaborate with other patient organizations to leverage combined resources on federal and state healthcare issues. However, there is an alarming and growing trend of insurance companies making medical decisions that only the patient’s healthcare professional should determine. In fact the IDF Medical Advisory Committee has issued a resolution explaining the danger posed by the arbitrary insurer requirement for a diagnostic vaccine challenge in previously diagnosed patients to re-establish a diagnosis of antibody deficiency, forcing patients off Ig therapy for several months (See page 3). The resolution will be disseminated throughout the industry to educate payers on the dangers of this policy.

This is truly a challenging time, and IDF wants to continue helping and empowering individuals living with PI. We are here to stand up to those who do not understand the needs of those with these rare, chronic disorders. Join us in this effort.

Know the Issues
The Foundation’s priority is to ensure individuals with primary immunodeficiency diseases have access to affordable treatment by the provider of their choice in the site of care appropriate to meet their needs. It is helpful to understand the issues that IDF helps people tackle on a regular basis.

Cost Shifting
Our largest concern is cost-shifting to patients. Typically if you have insurance, there are some costs that you pay out-of-pocket, which generally include deductibles, co-insurance and co-payments, or similar charges. The recent trend with some insurers and employers is to shift more of these costs to patients. Patients (with insurance) simply cannot afford high deductibles and co-insurance. IDF works to educate payers about the importance of putting patients first.

Cadillac Tax
Unfortunately, the “Cadillac Tax” is causing more cost shifting—employers are shifting costs to their employees in the form of higher deductibles, co-payments and out-of-pocket maximums to avoid an annual 40% excise tax on “high-priced” employer-sponsored health insurance plans, a part of the Affordable Care Act of 2010, which will begin in 2018. The tax affects more than very high-priced “Cadillac” or “luxury” employer sponsored healthcare plans, as was originally thought, and many employers are exploring ways to avoid the tax by lowering the cost of their health plans by shifting costs to patients and offering less choice. IDF participates in the “Fight the 40” coalition to promote elimination of this tax.

Specialty Tiers
Traditionally, commercial health insurers have charged flat co-payment fees for different tiers of medications: generics (Tier I), preferred name brand medications (Tier II), and non-preferred brand medications (Tier III). As an example, the co-pays might be set at $10/$20/$50 for the three tiers. Some commercial health insurance policies are now moving vital medications, mostly biologics such as immunoglobulin (Ig), which many patients with PI rely on, into “specialty tiers” that utilize high patient cost-sharing methods. These specialty tiers are now commonly requiring patients to pay a percentage of the actual cost of these drugs – from 25% to 40% or more – often costing hundreds, even thousands, of dollars per month for a single medication. Biologic medicines, such as Ig, have no generic or inexpensive equivalents. IDF works to ensure patients do not have to pay a percentage of the cost of a drug, only a fixed co-pay even if the drug is on a Tier III or higher.

Restrictive Formularies
Individuals living with PI need access to lifesaving medications and specialists. Restrictive formularies reduce product choice and quality of care, resulting in detrimental effects to patients.

Continuity of Care
Many people are offered a different insurance plan during the annual open enrollment period, often subjecting patients to changing doctors in order to stay in network and causing disruption to the patient’s care. A treatment lapse due to a requirement of obtaining a new authorization is especially problematic for those on weekly subcutaneous immunoglobulin (SCIG) when it can take weeks (several treatment cycles) to obtain authorization.

Have you experienced problems with access to care? We want to hear your story.
Contact IDF: www.primaryimmune.org/ask-idf or 800-296-4433.

For insurance resources, visit the IDF Patient Insurance Center: www.primaryimmune.org/insurance-center.
IDF Medical Advisory Committee Resolution Targets Dangers of Arbitrary Insurer Requirements

The Medical Advisory Committee of the Immune Deficiency Foundation (IDF) has issued a landmark resolution explaining the danger posed by the arbitrary insurer requirement for a diagnostic vaccine challenge for all previously diagnosed individuals with a specific type of primary immunodeficiency disease, Common Variable Immune Deficiency (CVID). CVID is a disorder in which affected individuals are unable to produce protective levels of antibodies, requiring life-long immunoglobulin (Ig) replacement therapy. Recently, dangerous and unnecessary guidelines regarding this life-saving therapy have been implemented by some insurers, and they are not consistent with the standard of care for people with CVID, causing extreme concern and prompting this critical resolution.

“We are especially troubled by a recent trend among some health insurers to require patients with an established diagnosis of antibody deficiency to present evidence that they have failed to produce antibody after vaccine challenge, even if their diagnosis was established years earlier,” the resolution states. “IDF supports this vaccine challenge requirement for newly diagnosed patients with IgG levels greater than 200 mg/dl, but not for individuals already receiving immunoglobulin (Ig) replacement therapy. This is because without this evidence, approval for continued Ig therapy is denied and patients are forced to stop treatment to perform the required assessment that will take several months.”

IDF has heard from many individuals with CVID who have been forced to go without their life-saving Ig therapy for five to eight months to meet this vaccine requirement mandated by insurers, risking serious or potentially fatal infection that would normally have been prevented by their Ig therapy. It is important to note that the vaccine challenge is not harmful itself. It is the stopping of Ig therapy that presents the danger to patients.

“This practice of insurers arbitrarily mandating that all established patients carrying a diagnosis of CVID must risk their health and well-being to submit evidence of vaccine non-responsiveness is both unnecessary and unjustified,” explains Rebecca H. Buckley, MD, Chair of the IDF Medical Advisory Committee and the J. Buren Sidbury Professor of Pediatrics and Professor of Immunology at Duke University Medical Center. “There are occasionally situations where immunologists may find it advisable to stop Ig replacement to perform a vaccine challenge, but these decisions must be made by qualified medical professionals acting on behalf of their patient’s best interests, not insurers.”

A professional immunologist has the appropriate training and experience to determine whether a recess in therapy to perform a vaccine challenge is necessary and appropriate, not an arbitrary mandate by the insurer.

IDF Retreats are weekend gatherings for everyone in the primary immunodeficiency (PI) community – patients, parents, siblings, partners or children. Discover the latest information and develop better approaches to living with PI – all while having a good time with a wonderful community! We also have special programs for individuals with Chronic Granulomatous Disease (CGD) and their families, as well as sessions dedicated to young adults, including one in Boston for all young adults and another in Salt Lake for young adults with ADA-SCID.

**Highlights**
- Outstanding Educational Presentations
- Valuable Life Management Sessions
- Opportunities to Share Experiences
- Interactive Exhibits
- Fun Youth Programs
- Informative Volunteer Sessions
- Special CGD Programs
- Innovative Young Adult Program (Boston)
- Young Adult with ADA-SCID Session (Salt Lake City)

**Topics Presented**
- Primary Immunodeficiencies & General Care
- Dealing with Respiratory Issues
- Autoimmunity & Immunodeficiency – What's the Relationship?
- Managing Gastrointestinal Complications
- Living Life to the Fullest with PI
- Clinical Trials – What to Consider
- Complementary & Alternative Medicine
- Ig Therapy – Practical Concerns
- Health Insurance – Get the Facts
- PI Life Stages Panel

**Registration Information**
Registration covers your hotel room for 2 nights, meals (Friday dessert reception, Saturday breakfast, lunch and dinner, Sunday breakfast) and all sessions and activities. Space is limited and registration is on a first-come, first-serve basis.

- **Individual $130** (1 person, includes one hotel room)
- **Family $210** (2-4 persons, includes one hotel room)
- **Family $340** (5-8 persons, includes two hotel rooms)

*IDF Retreats are supported by charitable donations from Baxalta Incorporated, CSL Behring, Grifols, Horizon Pharma, IgG America | ASD Healthcare | US Bioservices, and Sigma-Tau Pharmaceuticals.

*Schedule subject to change.*
Last year, IDF Walk for Primary Immunodeficiency was held in 11 cities, reached over 3,500 walkers and raised a monumental $1 million! This brought the grand total of funds raised to over $2 million since the first walk in 2013. We thank all who participated, with special recognition to IDF Order of the Zebra members who raised $1,000 or more—81 reached this exclusive level!

Join the fun in 2016 for IDF Walk for PI as we bring together an awesome community and raise critical funds for the future of those living with primary immunodeficiency diseases (PI). In addition to funds raised, the walks provide unique opportunities for individuals and families to connect with each other. For some, it is their first time meeting someone else with PI. For others, it is a pleasant reminder that they have a strong community behind them and they are not alone. These outcomes are a direct result of the tremendous efforts of our participants and the support of our sponsors.

**2016 National Presenting Sponsor:** Baxalta Incorporated

**2016 National Sponsors:** Coram CVS/Specialty Infusion Services, Grifols, Horizon Pharma, IgG America | ASD Healthcare | US Bioservices, Kedrion Biopharma

**IDF Walk for Primary Immunodeficiency 2016**  
**Registration Now Open!**

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

**Nationwide Virtual Walk - All Year Long!**

Questions? Contact IDF:  
walk@primaryimmune.org or  
800-296-4433

[www.walkforPI.org](http://www.walkforPI.org)

Follow “IDF Walk for Primary Immunodeficiency” on Facebook:  
[www.facebook.com/WalkforPI](http://www.facebook.com/WalkforPI)
Mark the Shark: How One Young Boy Earned His Nickname

Just before he turned 4, Mark Spinelli, Jr. was diagnosed with Common Variable Immune Deficiency (CVID). Like many young children, Mark had a difficult time understanding the many doctor visits and the “really big needles.” Within a year, he began questioning things that no 5-year-old should be considering. He knew he was different from the other kids in his class, but he couldn’t understand why and became angry. But over time, with the support of his family and friends, and with a little help from IDF, Mark has come into his own and earned the nickname ‘Mark the Shark.’

“Hearing that your child has a life-threatening illness is hard enough, but what makes a scary situation even worse is when you’ve never even heard of the illness,” explains Nicole Spinelli, Mark’s mom. When Mark became frustrated and resentful of his weekly immunoglobulin infusions, Nicole and her husband Mark Sr. became desperate for ways to help their son. That’s when they found IDF.

Initially, the IDF website was just a resource for the eager parents, learning all they could about primary immunodeficiency diseases (PI). They tried to show Mark the games and books, but he refused to acknowledge their existence. In fact, discussion of CVID around him was forbidden by Mark, making it very clear that no friends, coaches, teachers or anyone was to know that he had CVID. Mark said, “I don’t want anyone to treat me differently because of what I have! It is not who I am!”

His parents were at a loss when the IDF newsletter arrived with information about the IDF 2015 National Conference. They thought maybe meeting other kids with PI could help Mark understand that he wasn’t alone in all this. After initially saying no, Mark agreed to attend the conference. For the first time since Mark was diagnosed, the Spinelli Family felt hope, and Mark enjoyed the conference. But upon returning home to New Jersey, Mark said, “That was great—thanks, Mom—but you know we are never discussing this again, right?”

Mark’s parents complied until an e-mail about forming a team for IDF Walk for Primary Immunodeficiency in New York City arrived. “It was as if IDF knew Mark once again needed something,” explains Nicole. “Very carefully, I approached him, and this time it wasn’t about having CVID, but it was about what he can do because of having it. He asked if he should be proud of himself for having CVID and all he does, and I said, ‘of course.’” Mark went to the computer, looked over the walk website and signed in as ‘Mark the Shark.’

The immediate initiative Mark took was both surprising and inspiring to his family and friends. Driven to raise money for research, Mark found creative ways to raise money. With a team of 75 people and raising $16,620, Mark the Shark found new inspiration. But he wasn’t the only one in his family touched by the walk—Gabriella and Frankie, Mark’s younger sister and brother, supported him, not just with his fundraising but also during his regular infusions. The walk meant just as much to them as it did to Mark.

The night after the walk in NYC, Mark had to do his infusion for the week. Exhausted from the day, sitting in his Team Mark the Shark t-shirt and the Order of the Zebra medal hanging from his neck, he sat there ready to go—no argument, no questioning, and no anxiety. This was a long way from five years ago when Mark was diagnosed and the difficult years that followed.

Thanks to the Spinelli family for sharing your story! Do you have an inspiring story to share? Contact IDF: 800-296-4433 or info@primaryimmune.org.
April: National Primary Immunodeficiency Awareness Month
World PI Week, April 22-29

Are you tired of nobody knowing what primary immunodeficiency is? Well, April is the perfect opportunity for you to help promote awareness! Increasing awareness of primary immunodeficiency diseases (PI) is absolutely critical for earlier diagnosis and appropriate treatment, not to mention more understanding of these rare, chronic conditions. To get you started, below are ways you can help. Have fun, be creative and help increase awareness of primary immunodeficiency!

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 IDF says THINK ZEBRA! This April wear your favorite zebra attire (and encourage your friends, family and coworkers to do so too!), post your photos to IDF Friends, Facebook, Twitter or Instagram, and send them to IDF: idf@primaryimmune.org.

Share IDF “Learn More” Poster
IDF programs and resources produce benefits for thousands of people living with primary immunodeficiency, but people need to find IDF first! We developed the Learn More – IDF Awareness Poster to lead patients and family members to IDF to use our services and innovative materials. Start in your community! Are you a member of Facebook groups or other online communities related to primary immunodeficiency? Share the poster with them! You can download or order awareness posters, information cards and IDF publications to distribute at libraries, clinician’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 idf@primaryimmune.org or 800-296-4433.

Contact Local Media
Tell your story to the local media with the help of our Media Kit, which includes steps on how to go about contacting the media, sample letters and press releases, FAQs about primary immunodeficiency 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!

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

Show Us What You Did & Take a Selfie - #IDFselfie
Make sure you tell us what you did to promote awareness in your community, and make sure you take a selfie whenever you are wearing your zebra attire and promoting awareness! Submit your stories and pictures for the IDF Blog and/or the IDF ADVOCATE newsletter: idf@primaryimmune.org.

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

Spread the Word on 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 #thinkzebra
• Download custom profile and cover photos at: www.primaryimmune.org/awareness

SPRING 2016
“How Can I Have an Allergy If I Have a Weak Immune System?”
Understanding Allergies and Primary Immunodeficiency

By Joshua D. Milner, MD
National Institute of Allergy and Infectious Diseases, National Institutes of Health

Having allergies when you also have a primary immunodeficiency can make anyone’s head spin (or sneeze). Allergies are tricky enough as it is, with different definitions of what an allergy is, to different types of allergies, triggers and responses. But allergies in folks with primary immunodeficiency diseases (PI) present a series of unique challenges. A question we often get is, “How can I have an allergy if I have a weak immune system?” The answer is that in almost every case, having a PI makes only part of the immune system weak. And besides fighting infection, a typical immune system also needs to know how to stop fighting that infection, and to figure out when it isn’t an infection at all. So if one part of the immune system isn’t working well at fighting an infection, it also might not work well in preventing another part of the immune system from going rogue.

There are a number of other reasons allergies occur often in PI. One is that the types of infections, or even the type of resident bacteria and viruses in the gut and skin, can increase one’s risk for allergy. Another is that people with PI often have to take life-saving medicines such as antibiotics, and often intravenously (IV). Increased exposure to medications, especially by IV, no matter who you are, increases one’s risk for allergies to those medications.

Finally, there are quite a few allergies directly caused by certain genetic mutations that cause PI to begin with. In some cases we really don’t know why, such as the increased risk for eczema and food allergies in Wiskott-Aldrich Syndrome, having really high IgE—the antibody that causes allergies—in the Autosomal Dominant Hyper-IgE syndrome due to STAT3 mutations, or the raft of allergies you can get with DOCK8 deficiency. In other cases we do know why, such as PLAID (PLCG2 associated antibody deficiency and immune dysregulation) where a mutation in PLCG2 actually leads the protein to turn on only in the cold. When that happens in mast cells—the cell that produces histamine in an allergic reaction—it causes something called “cold urticaria,” or hives to the cold.

One of the challenges is knowing when it’s an allergy. When you get frequent sinus infections, are they really just caused by the bug or could symptoms be due to an allergy to, say, dust mites? Or is it both? The swelling that allergies can cause in the sinuses makes it easier for bugs to grow there and harder to drain them. Other folks can get diagnosed with recurrent pneumonias, when in fact they are asthma attacks in the context of a cold with fever, which can even look like pneumonia on an X-ray.

To approach these issues, a great start is to have an open mind to the possibility that allergies might be contributing to a problem and get evaluated by an expert allergist/immunologist who understands allergies and the immune deficiency. There are skin tests and blood tests which help make the diagnosis, but they are only guides and never should be used on a fishing expedition to look for some magic allergen that is the root of all the problems—that rarely ever happens. It is critical to also be aware that many issues are not at all related to allergies. Distinguishing fact from fiction is always difficult in medicine, and allergies in the context of PI might be one of the hardest tasks. Getting good reliable information, paying close attention to how your body reacts to many things, and becoming aware of the signs of allergies can help achieve it.

For more about allergies and PI, go to: www.primaryimmune.org/allergies.
In 2014, there was a widespread outbreak of respiratory illness in the U.S. caused by a virus called Enterovirus-D68 (EV-D68). Because an infection caused by EV-D68 is rare in the U.S., the Immune Deficiency Foundation (IDF) became concerned that the donor population from which current batches of immunoglobulin (Ig) products were made might have low levels of protective antibodies to this virus strain. With the help of the Plasma Protein Therapeutics Association (PPTA) and Centers for Disease Control (CDC), a study was conducted to determine if current Ig products contained antibody to EV-D68 and if patients with primary immunodeficiency diseases are being protected.

In the August 2015 issue of the *Journal of Clinical Virology*, Y. Zhang and colleagues from the CDC reported the results when they tested the supplied Ig preparations for neutralizing antibodies against an earlier stored sample of EV-D68 virus and three EV-D68 isolates representing the types that circulated during the 2014 outbreak. All commercial lots of Ig tested were obtained from U.S. donors, and all were positive for anti EV-D68 neutralizing antibodies with high titers of protective antibodies and with comparable median titers to all four EV-D68 viruses.

For more information, go to: [www.primaryimmune.org/enterovirus-d-68](http://www.primaryimmune.org/enterovirus-d-68).
stopped drowning in paperwork!

how one mom uses IDF ePHR

most parents who have a child with a primary immunodeficiency disease (PI) have some kind of medical binder or files filled with paperwork from over the years. For that matter, anyone who is living with PI probably has a stack of medical binders or files and has felt like they are drowning in paperwork. Over the past two years, one mom has been using IDF ePHR, the electronic personal health record designed for the PI community, and she wants others to know that it can really help manage what can be an overwhelming amount of information.

record pretty much everything

Kathy Owl Green, RN, MBA, BSN, CPN has been a pediatric nurse at Texas Children’s Hospital for 25 years. Chase, her 6-year old son, has been sick 2-3 weeks out of every month for most of his life, including asthma since he was 4 months old, 13 ear infections, six bouts of pneumonia, two hospitalizations, and multiple MRSA infections, yeast infections and sinus infections. His doctors are currently trying to identify his exact genetic defect.

Chase’s story is not unlike so many living with primary immunodeficiency. The list of infections, medications, diagnoses can be long, and the details associated with each are important to track. Kathy uses IDF ePHR to record Chase’s daily peak flows and symptoms. “My son has lots of chronic pain and it helps me keep track of how often it is happening and where the pain is,” she says.

“I record all medications he is on—chronic and intermittent. I chart his diagnoses and lab results. Previously I was keeping all this in an Excel spreadsheet, but I was not able to harvest the data in a usable format.”

generate reports that make sense

Kathy loves being able to run reports to show Chase’s providers his medical information or pain history. “When you talk about the frequency of symptoms, it makes a bigger impact when they can see the entries daily and see that he has issues every single day of his life despite the fact that when you look at him he looks great on the outside.”

She admits, “Also his mom (me) is a little forgetful and I don’t often remember how many times he is sick or how often he has complaints of pain. Using it helps paint a clearer picture.”

planning for her son’s future

Kathy is looking ahead as she uses IDF ePHR for Chase. “He is only 6 years old. As he gets older he will change providers and lose access to his medical information. By keeping his ePHR up to date, this will give him a lifelong medical history that he can share with any providers he sees in the future.” Like most 6 year olds, Chase is into super heroes, Legos, and his iPad—maybe one day he can use IDF ePHR on his iPad.

IDF ePHR – invaluable resource

She even recommends IDF ePHR to her patients. “First, I tell our new infusion patients about the IDF, and then I often open the ePHR to show them how to use it … It is really helpful to find a community to support you on your journey and since the IDF was made by parents for parents, it is an invaluable resource.”

Kathy encourages parents, individuals—anyone trying to keep track of medical information and avoid drowning in paperwork—to use IDF ePHR.

To start tracking your health information, create an account at: www.idfephr.org.

Watch Our New Video about IDF ePHR & PI CONNECT:


IDF ePHR is exclusively sponsored by CSL Behring.
Raise Your Hand
IDF Volunteer Opportunities

The Immune Deficiency Foundation (IDF) wants you to help make a difference in the primary immunodeficiency community by becoming a part of our nationwide network of dedicated volunteers. As an IDF volunteer, you will have many opportunities to enrich the lives of others by sharing your time and talents. Whatever your interests or skills may be, we have an opportunity for you.

IDF Walk for PI Volunteer – Lend a Hand to IDF’s Largest Fundraising Event
Opportunities are available in cities where walks are held or through our volunteer-led community walk program.

Community Outreach – Join the Movement to Spread Awareness
Build relationships with healthcare providers, legislators, and patients & caregivers, or speak to staff members and donors at plasma centers about their lifesaving commitment to the PI community.

Patient & Family Support – Support Individuals in the PI Community
Provide support to individuals with PI and family members online, face-to-face or over the phone.

Virtual Volunteering – Get Involved in IDF’s Social Networks

Legislative Advocacy – Make a Difference through Public Policy
Impact the outcome of important legislative decisions by communicating with legislators about state and federal public policies that affect those living with PI.

Group Leadership – Make Connections & Enrich the Lives of Others
Join a team of dedicated volunteers who help to plan and organize regular support group meetings in their local area for individuals with PI and their family members.

One Day Service Opportunities – Take Initiative in Your Local Area
Donate your time and talents to assist IDF staff at an IDF sponsored event in your local area. We offer a variety of one day volunteer openings across the country for those who have limited free time available.

Who Is Eligible to Volunteer?
Patients. Family members. Friends. We encourage anyone who wants to help advance the mission of IDF and support the PI community to volunteer.

Learn more: www.primaryimmune.org/volunteer
volunteer@primaryimmune.org
800-296-4433

WITH GRATITUDE
MEMORIAL GIFTS
November 1, 2015 - February 1, 2016

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Holli Jo Bess
Kristin Buyer
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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, go to: www.primaryimmune.org/give.

Alternatively, you can mail your gift to Immune Deficiency Foundation, 110 West Road, Suite 300, Towson, MD 21204.

Questions? Contact IDF: 800-296-4433 or e-mail: development@primaryimmune.org.
For an Updated IDF Calendar of Events, Visit
www.primaryimmune.org/event-calendar.