Promoting Herd Immunity in Your Community

With four boys ranging from ages 9 to 15, every day is busy for the Green family of River Forest, Illinois. There is always something happening, from finishing up homework to rushing to soccer practice. But in the midst of the Green family’s busy schedule, mom Sonia makes time to get out a simple message to all parents: Vaccinate your children to keep my children healthy.

Sonia, a law professor, and her husband Colby, a lawyer, are the parents of Harrison (15), twins Holden (10) and Langford (10), and Davis (9). Harrison, Holden and Davis have X-Linked Agammaglobulinemia (XLA), a type of primary immunodeficiency disease (PI) characterized by the body’s inability to make antibodies. People with XLA do not make any protection for themselves when they are vaccinated. “Many people view vaccination as a choice, not a must,” she said, “I’ve made it my mission to educate people that if they choose not to immunize, it could literally be fatal to my children.”

Sonia and Holden were recently featured in a National Public Radio story for advocating for herd immunity, or community immunity. Herd immunity occurs when most of a population is immunized against a contagious disease, such as measles or mumps, and, for the most part, everyone in that population is then protected against the disease because an outbreak is less likely. However, for many years, some Americans have taken herd immunity for granted, thinking that infectious diseases that were once common, such as polio, measles or whooping cough, have been wiped out. The success of national immunization programs has made many complacent and caused them to think that vaccines are optional. As a result, herd immunity is being threatened.

In April 2014, the IDF Medical Advisory Committee published an article in The Journal of Allergy and Clinical Immunology that reviewed the current body of knowledge about vaccines. The article made recommendations about specific vaccines for people with different kinds of PI and addressed the concerns those with PI had about getting vaccine preventable illnesses. The article emphasizes educating parents and physicians about the critical need for everyone to be vaccinated in order to maintain herd immunity. The article states, “Parents who elect not to vaccinate their children are actually placing themselves and their children at increased risk of serious infection and even death... The increased risk of disease in the pediatric population, in part because of increasing rates of vaccine refusal increases potential exposure of immunodeficient children.” Essentially, parents who choose not to vaccinate their children not only put their families at risk of serious infection and even...
death, but they also put those with PI directly in harm's way, like Sonia's sons. “My boys get monthly infusions of intravenous immunoglobulin, or IVIG, which provides them with some of the immunoglobulins (antibodies) that they are lacking, and they take a nightly antibiotic,” she explained, “Still, despite this medicine, my sons are still vulnerable to disease.”

Many don't realize that childhood diseases, such as chicken pox and measles, are dangerous. Here are just two recent examples of the dangers posed by unvaccinated populations:

- The annual number of U.S. whooping cough (pertussis) cases has climbed to over 41,000 cases, killing 10 children in California in 2010.
- In the first five months of 2014, the U.S. had 288 cases of measles. About one in seven of those people were hospitalized, and about 90% of those who contracted the disease were unvaccinated.

In addition to the dangers from complacency, some have falsely accused vaccines of contributing to everything from autism to ear infections. The reality is that vaccines are safe, and they are estimated to save 6 to 9 million lives per year. But more members of the PI community must help spread the word, as Sonia is doing.

### Make It Personal

Telling your personal story can make a surprisingly large impact. Sonia noted, “I've found the most effective way to educate people is to make it personal.” In her blog post** for VoicesforVaccines.org, Sonia said, “If you are a parent who is vaccine-hesitant or who has chosen not to vaccinate, my plea to you is this: My kids are my heart and soul, just as yours are to you, and I need your help to keep them healthy and safe. I would do the same for you.”

Katerina (Katia) Birge, a 30-year-old Denver resident with Common Variable Immune Deficiency (CVID), is another example of how telling your personal story can help people understand the importance of herd immunity. She successfully advocated for Colorado HB1288. In its original form, the bill would have required that parents talk with a medical professional or go through an online education module before they would be granted a personal belief exemption from vaccinations, something California and Oregon have recently moved to do. By the time the bill received the final vote, however, the education component was gone. But the bill does require Colorado schools and daycares to make their vaccination rates public on request and potentially changes how often parents who do not agree with vaccination have to sign a personal belief exemption.

“It’s a start, but we are going to need to push a stronger version of the bill next session,” explains Katia, “My involvement with the bill was kind of an accident. After I stopped working as a journalist…I interned with Dr. Irene Aguilar, a state senator. Her office started working on this bill, and it just happened to apply to me personally. I contacted the Colorado Children’s Immunization Coalition and asked what I could do to help increase herd immunity. I used social media and attended every town hall meeting that I could to tell my story.”

Katia added, “Dr. Paul Offit appeared on the Colbert Show, which helped to spread the word about the importance of vaccines. We connected with IDF, the National Hemophilia Foundation and many others. I never saw so many people put aside their egos to pass this bill. We received hate mail and had to make some concessions, but the bill was signed into law in May.”

“I learned that not everyone is willing to listen,” she continued. “Social media, engaging celebrities, talking to your friends and neighbors, all help. At first, my friends thought it was too much of a bother to get the flu vaccine, but once I could make it personal, people started to understand.”

### What Parents Can Do

Parents should communicate with schools, send emails or letters to the principal, nurse, and even science teachers about PI and immunizations. Sonia noted, “My kids’ science teachers were very receptive, then they asked the boys to share more, and invited me to come to talk to their class. One teacher even played the NPR piece for the class to make the kids more aware of ‘herd immunity’.”

Sonia encourages her boys to be advocates for themselves and be open to explaining PI. She also advises parents of children with PI, “Know what your child is most susceptible to and alert their school or work. For my boys, their weak point is their lungs. They’re susceptible to pneumonia, and viral meningitis scares me the most.”

Other measures parents can take to protect their children include avoiding play dates with non-vaccinated children and consider
keeping them home on days when there is a serious, infectious disease outbreak from which their immunoglobulin (Ig) replacement therapy would not protect them.

Ideas to Get Started
Take small steps to advocate for community immunity. Start with emails to friends and family. Ask them to educate themselves about non-vaccinating and know the risks. Post to Facebook or whatever social media tool you use. Submit a blog post to IDF or VoicesforVaccines.org. Comment on blog posts and news articles related to vaccination and emphasize the importance of herd immunity.

“Whatever you do, just talk about it,” Sonia recommended, “If I learn that someone’s new baby just got their shots, I share that on Facebook. And I make sure that my privacy setting ensures it can be shared. Tell your story. Make it personal – then people really get it.”

Learn more about advocating for herd immunity at www.primaryimmune.org/immunizations.

In all cases, parents and patients with PI should consult their healthcare providers for immunization recommendations and further information.

Specific Recommendations for Immunization of Children and Adolescents with Different Types of PI

<table>
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<tr>
<th>Category and Examples</th>
<th>Recommended</th>
<th>Contraindicated (Should Not Receive)</th>
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<td><strong>B-LYMPHOCYTE (HUMORAL) DEFECTS</strong></td>
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<tr>
<td>• Common Variable Immune Deficiency (CVID)</td>
<td>• Effectiveness of any vaccine is uncertain</td>
<td>• Oral Polio vaccine</td>
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<td>• Combined defects - pre-transplant Severe Combined Immune Deficiency (SCID) and pre-transplant Combined Immune Deficiency</td>
<td>• All vaccines are probably ineffective</td>
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<td>• Post-Transplant Severe Combined Immune Deficiency (SCID)</td>
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<td>Partial defects such as:</td>
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<td>• Effectiveness of vaccines depends on degree of immune competence</td>
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<td>• Chronic Granulomatous Disease (CGD)</td>
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<td>• BCG and Salmonella</td>
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<td>• Leukocyte Adhesion Defects</td>
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<tr>
<td>• Myeloperoxidase Deficiency</td>
<td>• Live viral vaccines are probably safe and effective</td>
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</tbody>
</table>

Adapted from “Recommendations for live viral and bacterial vaccines in immunodeficient patients and their close contacts,” The Journal of Allergy and Clinical Immunology, April 2014.
What Vaccines Patients with PI Can Safely Receive

Among the greatest scientific advances in the past two centuries is the development of effective vaccines. Many diseases that used to be epidemic, causing illness and death are now able to be prevented. Despite their proven efficacy in the population at large, vaccines can be problematic for people with primary immunodeficiency diseases (PI). Since some types of PI interfere with the body’s ability to make antibodies in response to vaccination, many would ask if it makes any sense to give vaccines to patients with PI. As part of the PI community, it’s important for you to have the facts about vaccines.

In April 2014, the IDF Medical Advisory Committee (MAC) published an article in The Journal of Allergy and Clinical Immunology called “Recommendations for live viral and bacterial vaccines in immunodeficient patients and their close contacts;” addressing the uncertainty regarding which vaccines can be given to patients with PI. The article also addressed the growing neglect of societal adherence to routine immunizations. IDF acknowledges the tremendous importance of the article and is grateful for the efforts of the MAC.

Not all people with PI have problems with vaccines. Those with phagocytic cell disorders, such as Chronic Granulomatous Disease (CGD) or with Complement Deficiencies, benefit from immunization. Patients with these types of innate immune disorders should absolutely receive vaccines to protect them.

However, people with T and B cell immunodeficiencies, such as Common Variable Immune Deficiency (CVID), Severe Combined Immune Deficiency (SCID) or Bruton’s agammaglobulinemia, are unable to develop protective immunity following vaccination, so the vaccines would not do them any good. Moreover, some vaccines may threaten the recipient. Live vaccines, such as the chicken pox vaccine (Varivax), measles, mumps, rubella (MMR), rotavirus, BCG, yellow fever, oral polio and the influenza nasal spray, could actually cause the disease it is supposed to prevent in individuals with these types of PI.

Infants with Severe Combined Immune Deficiency (SCID) are at the greatest risk for problems with live viral vaccines (LVV). Some live vaccine viruses can be found in the body fluids and stools of vaccinated normal individuals for up to two weeks following vaccination. Because of this, families should limit contact between individuals recently immunized with LVV’s and infants with SCID during that time.

For people with antibody deficiencies, immunoglobulin (Ig) replacement therapy is the standard of care. Ig provides these people with the antibodies that their own bodies cannot make, protecting them from vaccine preventable diseases.

The IDF Medical Advisory Committee recommends:

1. Education about the critical need for maintenance of herd immunity (community immunity) in the population at large. Herd immunity offers valuable protection to patients with PI who are unable to mount protective antibody responses. It is particularly important for family members of patients with defective T and B lymphocyte–mediated immunity to receive all of the available standard immunizations in order to protect their family member with these types of PI.

2. Avoidance of live viral and bacterial vaccines in all patients with significant T- and B-cell deficiencies. Early diagnosis of these conditions is critical, particularly in infants. Standard immunizations given to infants at 2, 4 and 6 months of age include the rotavirus vaccine which is a LLV. In those states with newborn screening for SCID, via the T-cell receptor excision circle (TREC), infants with low T-cell numbers can be identified shortly after birth. Live viral and bacterial vaccines should be deferred in these infants until they are evaluated by an immunologist. Similarly, any infant born into an extended family with a history of SCID should also have these vaccines held until he/she is evaluated by an immunologist. This latter precaution is particularly important for high-risk families living in states that do not have TREC–based newborn screening.

3. Determination of the degree of immune reconstitution in patients treated with stem cell/bone marrow transplant, enzyme therapy, or gene therapy before live vaccines are given. These individuals should only be vaccinated after consultation with a clinical immunologist proficient in the diagnosis and management of PI who can explain the risk/benefit ratio for parents or patients.

4. Parents need to balance the need of the immunoreconstituted child (post-transplant SCID) to be protected from exposure to infection from live vaccines and close contact–transmitted vaccine-derived infection with the need of the child to integrate into society and develop social and learning skills in group environments.

For a person with PI, vaccines are an important weapon in the arsenal to prevent infection and stay healthy. People with PI, their parents and family members should consult their immunologist and primary care providers to determine the need for vaccination.

For more information, visit www.primaryimmune.org/immunizations.

In all cases, parents and patients with PI should consult their healthcare providers for immunization recommendations and further information.

A special thank you to the IDF Nurse Advisory Committee for their work developing this summary and adapting the recommendations chart, which appears on page 3, from the MAC article.

http://primaryimmune.org/idf-medical-advisory-committee-publishes-vaccination-recommendations/
Patients living with PI, family and friends will walk in six cities this fall for IDF Walk for Primary Immunodeficiency! This second year of the walks will include three additional cities and offer more incentive prizes for the biggest fundraisers.

IDF Walk for Primary Immunodeficiency will be held in the following cities:

- **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

Don’t worry—you can still participate even if you cannot make it to one of the sites! You can make an enormous impact by creating a Virtual Walk Team. As a virtual walker, you will have access to the exact same fundraising tools as those at the physical sites, and be eligible for the same great incentive prizes.

The teams have gotten off to a strong start raising funds and earning cool prizes*, which include:

- **Raise $100 = Walk for PI T-shirt**
- **Raise $250 = Walk for PI Tote**
- **Raise $500 = Walk for PI Sweatshirt**
- **Raise $1,000 = Walk for PI Bluetooth Speaker**
- **Raise $2,500 = Walk for PI Daypack**
- **Raise $5,000 = Walk for PI 3-in-1 Coat**

Individuals who raise $1,000 or more on their personal fundraising page will be inducted to the IDF Order of the Zebra and receive special benefits at the walk.

*Prizes will be awarded after the walk.

Learn more and register for IDF Walk for Primary Immunodeficiency at www.walkforPI.org.

We are grateful for the support of our 2014 National Sponsors.

**National Presenting Sponsor**
- Baxter International Inc.

**National Supporting Sponsors**
- Grifols
- CVS Caremark / Coram Specialty Infusion Services
- IgG America/ASD Healthcare/US Bioservices
- Vidara Therapeutics
- Walgreens – IG Therapy Program
Featuring innovative technology, the IDF ePHR uses a completely new online system to transform how patients with primary immunodeficiency diseases (PI) will manage their health!

Taking all the helpful features found in the original IDF eHealthRecord, the new IDF ePHR still offers a place for you to keep your information safe, secure and private at no cost. But it goes so much further! It improves on all the functionality, adding easy-to-use features as well as convenient tools to help patients live healthier lives. This one central location offers the latest advancements in health record system management.

**You can:**
- Access your information from your computer, or download the new app to access your information anywhere from your smartphone or tablet
- Track medications, supplements, diagnoses, symptoms, infections, allergies and more
- Record Ig infusions
- Track goals, set reminders and notifications
- View your progress in charts and graphs
- Create, share and print reports
- Utilize chronic disease management tools and keep track of all conditions
- Download medical records through Blue Button+ from participating providers
- Sync with Microsoft HealthVault to access information from various labs, pharmacy systems, personal health devices and health resources

If you already have an IDF eHealthRecord account, don’t worry, all your previously entered information will be in your new IDF ePHR account in September 2014. It couldn’t be easier!

So, no excuses! It’s time to simplify your life with the new IDF ePHR. It’s time to join the hundreds of patients and family members in the PI community and easily track and manage your health information. Remember, you can:
- Use your IDF ePHR anywhere, anytime
- Start accounts for family members and track everyone’s health
- Make time with your clinician more beneficial by sharing organized, comprehensive information about your health from your ePHR
- Prepare for unexpected emergencies
- Set healthcare goals and use personalized care plans to improve your health

For more information about the new IDF ePHR, e-mail info@idfephr.org or call 800-296-4433.

The IDF ePHR is sponsored in part by CSL Behring.
Be a Part of Research!
An added benefit for users of IDF ePHR is the opportunity to be a part of research by consenting into PI CONNECT, the new IDF Patient-Powered Research Network.

What Is PI CONNECT?
PI CONNECT connects the information you enter in your IDF ePHR, the online personal health record for patients with primary immunodeficiency (PI) with the United States Immunodeficiency Network (USIDNET) patient-consented registry, which contains clinical data on several thousand patients with PI. Bringing together this information through PI CONNECT gives researchers a better idea of the patient experience. Rest assured, your information is safe, secure and de-identified.

IDF was approved for a funding award for PI CONNECT from the Patient-Centered Outcomes Research Institute (PCORI). PI CONNECT will be part of PCORnet: the National Patient-Centered National Clinical Research Network. PCORnet aims to advance the shift in clinical research from investigator-driven to patient-centered studies, giving patients “a seat at the research table.” PCORI envisions PCORnet to be a secure, national data network that improves the speed, efficiency, and use of patient-centered comparative effectiveness research. PI CONNECT along with all networks in PCORnet will form a new national resource that aims to boost the efficiency of health research.

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Create Your IDF ePHR Account and Join PI CONNECT in 4 Easy Steps!

1. Create Your IDF ePHR Account
In September 2014, go to www.idfephr.org and click “Create Account.” You’ll be asked to enter your basic information.

The IDF ePHR is an easy way to safely and securely store your information in one place.

2. Begin Your First Record
You can create records for your whole family, but the first record you begin with should be for the person with PI. All other records that follow do not require a PI diagnosis.

Make sure to enter all required information, and accept the terms and conditions.

Those who have a PI will be asked to consent into PI CONNECT.

3. Join PI CONNECT
Join PI CONNECT, the IDF Patient-Powered Research Network, and be a part of research!

You will be asked to join, or consent into, PI CONNECT, which allows patient-entered data from your IDF ePHR to enter into the United States Immunodeficiency Network (USIDNET) patient consented registry.

Once you join, you can participate in research conversations on the PI CONNECT forum.

4. Start Using the IDF ePHR
Your IDF ePHR is your personal health record. Record your medications, track your infusions, set goals, reminders and notifications. Make it work for you!

Customize your ePHR and sync with Microsoft HealthVault to access information from various labs, pharmacy systems, personal health devices and health resources.

Make time with your clinician more beneficial by sharing organized, comprehensive information from your ePHR.

Most importantly, use IDF ePHR to help you live a healthy life!

Share Your Research Ideas
You can feel great about contributing your information to research to help improve care of patients with PI, but have you ever had an interesting idea for researchers to investigate? PI CONNECT gives you access to an exclusive research forum where you will be able to:

• See research questions as they are posed and offer your opinions about them.
• Propose your own research questions that matter to you.
• Track your own data and see how you compare to others with the same disease.
• Have your ideas heard and translate them into actions!

You can help guide research, and the information you share provides real-time information, giving researchers a better idea of the patient experience.

For more information, e-mail piconnect@primaryimmune.org or call 800-296-4433.
“Amazingly Supportive” People at IDF Retreat in Atlanta

“So thankful and very appreciative to be able to be a part of these wonderful retreats. I always learn so much and meet such wonderful people who are amazingly supportive.”

This was just one comment from an attendee from the IDF Retreat in Atlanta, held June 20-22, 2014. IDF Retreats are weekend gatherings designed for everyone in the primary immunodeficiency (PI) community to learn, meet others and find the support they need.

More than 230 people, including patients, parents, siblings, children and partners, from 24 states participated, and this was the first IDF event for approximately half of the attendees. All had the unique opportunity to learn how to develop better approaches to living with PI from healthcare, life management and insurance experts. They connected with others going through similar experiences and took part in interactive activities and fun entertainment, including a circus.

Adults listened to informative presentations, joined discussions and participated in Q&A sessions. There was a special afternoon session devoted to those living with Chronic Granulomatous Disease. During the youth program, the young attendees had fun while learning about the immune system and participated in some very spirited games of IDF Jeopardy. They discovered why IDF says THINK ZEBRA!, creating their own zebra masks. Tweens and teens were challenged with their “survivor skills.”

Attendees had positive things to say about the weekend:
• “I have learned a great deal this weekend. Thank you for putting the retreat together and making it affordable. Wonderful program and speakers.”
• “I always learn something new that helps me deal with PI.”
• “This was a great experience for both my children and me, and we will be attending future retreats.”

The IDF Retreat in Atlanta was a worthwhile experience for so many! Special thanks to our wonderful presenters:
• Rebecca Buckley, MD – Duke University School of Medicine
• Nichole Clark – IDF Patient Advocacy Manager
• Mary Ellen Conley, MD – The Rockefeller University
• Carla Duff, CPNP, MSN, CCRP – University of South Florida
• Jennifer Leiding, MD – University of South Florida
• Peter Mannon, MD, MPH – University of Alabama at Birmingham
• Donna Marie Meszaros, PhD – Abaris Behavioral Health and Apex Behavioral Health Western Wayne
• Peter Mustillo, MD – Nationwide Children’s Hospital & Ohio State University
• Jennifer Shih, MD – Emory University School of Medicine
• John Sleasman, MD – Duke University School of Medicine

Join us for the next IDF Retreat in Portland, OR!
September 5-7, 2014 • Embassy Suites Portland Downtown • To register, go to www.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.
IDF Common Ground is completely new and redesigned! In 2009, IDF first launched IDF Common Ground, a site just for teens with primary immunodeficiency diseases (PI). Five years later, the site was long past its optimal performance, so we developed this great new site to give teens with PI more ways to share, interact and connect with each other.

The new IDF Common Ground is mobile-responsive (ready for tablet and smartphone use), and visible to members only. No one may access any site content without first creating an account.

So if you are a teen living with PI, go to www.idfcommonground.org, click on the button that says “New? Sign up today!” and create an account to get started!

**Teens already enjoy the new site:**

“I think Common Ground is such a cool website! The idea that kids from all around the country, who struggle with a primary immunodeficiency, can communicate with each other through this website that is designed for them is so amazing! IDF has given us this awesome platform to get to know each other and even meet at teen escapes and retreats! Common Ground is super user friendly and set up wonderfully. I would definitely recommend making an account!”

—Amanda Jensen

“If I were to say anything about the new Common Ground it would be that it’s a great place to reconnect with old friends and meet new people going through similar circumstances. The layout is also way better than it used to be and much more user friendly. The forums have been made much easier to access and find something you can relate to or want to know more about.”

—Cole Henjum

Once you are logged into www.idfcommonground.org, if you have any questions, click the “How to Get Started” and “FAQ” links at the bottom of the page. And if you still have questions, or if you are having trouble signing up, e-mail IDF at idfcommonground@primaryimmune.org.

Please remember that the information on IDF Common Ground should not be used in place of a visit, consultation, or advice of your healthcare provider. If you have any healthcare related questions, you should call or see your clinician.

IDF Common Ground was made possible by an unrestricted educational grants from Baxter International Inc., CSL Behring, Grifols, IgG America / ASD Healthcare / US Bioservices.

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**For Our Youngest Members of the PI Community**

The Immune Deficiency Foundation (IDF) always keeps the youngest members of the primary immunodeficiency (PI) community in mind when developing programs and resources. Youth Programs are offered at every IDF National Conference, Retreat and Family Conference Day. These kid-friendly gatherings offer education and fun for children, up to age 18, who are diagnosed with PI or have a family member with this condition. While parents are attending educational sessions, their children benefit from programs developed especially for them, helping them understand PI and connect with others going through similar circumstances.

**IDF publications** are valuable resources to help children and parents learn about living with PI. The *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases* includes chapters devoted to each life stage, from infants to adults, complete with advice for parents of children with PI, including how to help them understand their disease, normalize their life and coordinate their healthcare. IDF’s popular *Our Immune System* children’s storybook, which has been translated into many different languages, educates children about PI through illustrations as the characters explain how the immune system works and describe treatments.

The *IDF Arcade*, featured on www.primaryimmune.org, contains games inspired by the characters from *Our Immune System*. One of the most popular games from the IDF Arcade, Whack-A-Germ, now has an app. In the Whack-A-Germ app, players get the satisfaction of whacking the germ while watching out for the friendly T-cells and phagocytes. With colorful graphics and fun music, this app is great for little zebras. You can download the Whack-A-Germ app to your smartphone or tablet. It is available for free from Google play (Android) and the iTunes store (iOS). Search for “IDF Game.”

For more information about the IDF Youth Program, publications and Whack-A-Germ app, go to www.primaryimmune.org.

The *IDF Arcade* was made possible by an unrestricted educational grant from IgG America, ASD Healthcare, and US Bioservices.
No one should have to choose between paying their mortgage and obtaining medicine that can mean life or death. Yet, that’s just what has been happening across the U.S. for some patients living with primary immunodeficiency diseases (PI). The Immune Deficiency Foundation (IDF) is working to stop this by advocating for legislation to limit patient costs for lifesaving medication.

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) replacement therapy 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. These practices are placing medically necessary treatments out of reach for average Americans.

Biologic medicines, such as Ig therapy, have no generic or inexpensive equivalents. In addition to patients with PI, affected patients include certain types of cancer like leukemia and lymphoma, multiple sclerosis, rheumatoid arthritis, psoriatic arthritis, lupus, hemophilia, Crohn’s disease, and other conditions. Some of these patients currently endanger their health by skipping doses or go without treatment altogether due to excessively high cost-sharing.

IDF is advocating for H.R. 460, the Patients’ Access to Treatments Act, which seeks to restrain high out-of-pocket costs for specialty medications like Ig therapy. Introduced by Rep. David McKinley (R-WV) and Rep. Lois Capps (D-CA), this bipartisan legislation will help ensure patients with chronic, disabling and life threatening conditions access to the treatments they need. It would limit out-of-pocket costs for medications in a specialty drug tier (typically Tier IV or higher) to the dollar amount applicable to the drugs in a non-preferred brand drug tier, making it easier for patients to afford their needed medications.

The annual IDF Advocacy Day on Capitol Hill, held May 8, focused on gaining Congressional support for H.R. 460. More than 40 patients from 26 states held nearly 100 meetings with their Representatives and Senators. It was a productive day resulting in new co-sponsorships and an increased awareness of the challenges faced by patients who rely on lifesaving medication. IDF Advocacy Day is supported by charitable donations from Baxter International Inc., CSL Behring, Grifols, and IgG America / ASD Healthcare / US Bioservices.

If you or someone you know is facing a high specialty tier co-insurance for Ig therapy, please contact IDF immediately. Call 800-296-4433 or submit our online form: www.primaryimmune.org/services/ask-idf

You can add your voice in support of H.R. 460. Scan this QR code to send an Action Alert to your Members of Congress and ask them to take a stand against high out-of-pocket costs for patients with PI!

www.capwiz.com/immune/issues/alert/?alertid=62915366&type=CO
Jane and Bruce Holly have chosen to include IDF in their estate planning, making them the newest members of the IDF Legacy Society. The society recognizes those who have included IDF in their wills or who have created other types of planned or legacy gifts. According to Jane and Bruce, no matter how small or large of a gift someone can make, it certainly is worth looking into this type of giving. They said, “If you or any member of your family has PI, the thought of making a difference in the future is worth it.”

Jane and Bruce’s daughter, Lisa, was diagnosed with a PI when she was 14 years old. When they found IDF, they learned that they were not the only parents with a child struggling to understand and live with PI. As IDF developed and expanded their services, Jane and Bruce were impressed with the resources and information available to patients and families. “The meetings held for the patients, families and other care givers have been a great benefit to our family. Seeing the grassroots efforts of getting legislation passed to help all patients with PI has been very impressive,” they explained, “We hope with our legacy gift will fund more research and advocacy and that sometime in the future, others will not have to struggle with these diseases.”

It took several years for Lisa to be correctly diagnosed, and they were frustrated seeing her repeatedly contract one illness after another without knowing why. Finally, after years of being sick and months of testing, Lisa received her diagnosis and started treatment. Today, she is doing well and continues to receive regular immunoglobulin therapy. Her parents said, “We have been blessed with a great medical team who has allowed our daughter to grow and mature, graduate from college, obtain a master’s degree, be the Director of Education for a historical site, marry and have two wonderful children.”

In their estate planning, Jane and Bruce feel blessed that they have the capability to form a Charitable Remainder Trust (CRT). This type of trust is beneficial to both the donor family, and the recipient in that the family receives a designated percentage of the trust’s value each year while the recipient will receive the remainder upon their passing.

IDF is grateful for the generosity of Jane and Bruce, and wishes Lisa and her entire family well. 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.