True Friendships Begin at IDF Teen Escape

“I think we clicked because we had something in common, something that would change someone’s life in a second,” explains 16-year-old Haley Malloy, describing the friends she made at the Immune Deficiency Foundation’s Teen Escape. “We could act normal around each other. We didn’t have to hide who we really are.”

Every teenager wants to experience this—the feeling of being around other kids who just get you, the feeling of true friendship. Haley and three other teens discovered that feeling at IDF’s Teen Escape held last November in King of Prussia, PA.

Adam Brock from Hummelstown, PA, Ashley Caldwell from Penndel, PA, Bryan Jirsa from Joppa, MD and Haley from Kingston, NH met at IDF’s popular weekend experience exclusively for teens with primary immunodeficiency diseases (PIDD). Although they live hours apart from one another, they remain in close contact through text, IDF Common Ground, Facebook and web video chats.

The conversations came easily among the teens and their parents at Teen Escape. Seventeen-year-old Bryan explains, “The four of us and our parents just gravitated towards each other, and we had a blast the entire time.”

The bonds formed naturally, and their parents witnessed the positive impact Teen Escape had on their children. “Before the Teen Escape, Bryan had only met a handful of adults who had a PIDD,” says Karen Jirsa, Bryan’s mom, “It really didn’t sink in with him until he met other teenagers. It gave him an opportunity to meet others who have the same disease as him. He is in charge of his PIDD, and I believe that the Teen Escape helped with this!”

“(Teen Escape) is a great way to meet other kids who share similar life experiences,” says Colleen Brock, mom of 17-year-old Adam.

Michele Naismith, Haley’s mom, encourages parents to get their children involved, “Please ‘force’ your child to attend the one day workshops, the National Conference, the Teen Escape weekend, any and all events that IDF holds, and I guarantee you will not be disappointed and neither will your child … It was so important for me as a parent to recognize that my obligation to teach my child to cope with her disease was more important than my protective factor to shield her from the truth of primary immunodeficiency diseases.”

Coping with PIDD is challenging for any patient, but being a teenager complicates life even more. IDF developed Teen Escape to not only educate teens during a crucial time in their lives but also to create a community among them and foster friendships. No matter when you are diagnosed, whether as a baby, as a teen or some time in between, it makes an incredible difference to have a friend who knows what you go through and totally relates to you.

“I can open up to them about certain health problems, and I know that they won’t judge me or anything like that,” explains Haley. “I feel safe talking to them.”
Thanks to modern communication the four teens keep opening up and talking. They have become a support system for one another through regular texts and frequent video chats. The friends plan to reunite this summer at Hersheypark in Pennsylvania, close to Adam’s home. They want more time to joke around with each other.

According to Haley, “We all like to have fun and be kids. I hadn’t felt like a real teenager in a long time and when I was with them they brought me back to my childish self. It was a wonderful feeling.”

Adam agrees, “They are very nice people, and I can’t wait to hang out with them more.”

The four will definitely hang out more because they were recently accepted to IDF’s Teen and Young Adult Council. Each year teens apply for a limited number of positions on the council. Applicants must be active in their community, display strong leadership qualities and commit to helping teens through IDF. Council members share stories and offer support to other young patients with PIDD and serve as leaders at IDF events.

“I hope I can help others if they have questions and try to answer them,” says 18-year-old Ashley, “When I first was diagnosed, I didn’t know anything and I want to help others know more when they are first diagnosed.”

Bryan wants other teens to know that there are other kids that understand what is going on and want to help. When asked what advice he has for other teens with PIDD, he says, “You should embrace the things you have and be proud.”

Adam, Ashley, Bryan and Haley want to share their stories, to support other teens with PIDD and to help others create true, lasting friendships like the ones they now have. The four friends encourage teens to visit www.idfcommonground.org and make connections, and they strongly suggest attending a Teen Escape, simply put, “because the escapes are awesome!”

IDF Teen Escape is a weekend retreat exclusively for teens with PIDD. Each teen participant is accompanied by a parent. Mark your calendar for this year’s Escapes: August 2-4 in Cincinnati, OH and September 7-9 in Houston, Texas. For more information, contact IDF at 800.296.4433 or idf@primaryimmune.org.
IDF Plasma Center
Partners Program

Plasma centers throughout the country play a crucial role in the lives of many individuals with primary immunodeficiency diseases who depend on plasma-based, immunoglobulin therapy to protect them from life-threatening infections. IDF has enjoyed a strong relationship with those centers because of their commitment to the collection of high-quality plasma and establishing the highest levels of safety and quality assurance. Our association with plasma center staff members, plasma donors, and our own volunteers who visit the centers has grown strong over the years to develop into the IDF Plasma Center Partners Program.

The program includes IDF fundraising and awareness initiatives along with volunteer visits arranged by IDF.

Thank you to our Plasma Center Partners:
• BioLife Plasma Services
• Biomat USA
• Biotest
• Cangene Plasma
• CSL Plasma
• Octapharma Plasma

How the Program Works

How Family and Friends Can Help

Through IDF Donate & Donate, part of the IDF Plasma Center Partners Program, family and friends can support IDF. One of the first questions newly diagnosed individuals with a primary immunodeficiency disease hear from family and friends is, “What can I do to help?” This is the perfect time to encourage them to find out if they can become regular plasma donors. Their plasma donations will help thousands of people living with primary immunodeficiency diseases. Then, they can contribute the fee they receive for their time donating plasma to the Immune Deficiency Foundation “in honor” of a patient.

It is a double giving program – Donate & Donate – first donate plasma to help produce lifesaving immunoglobulin and then donate the payment received to IDF to support vital programs and resources.

The new IDF Plasma Center Partners blog www.idfplasmacenterpartners.org showcases all the ways that our partners—volunteers, plasma donors and participating plasma centers—are making a difference in the IDF community through this program.

Julie Fetch and U.S. Representative Fred Upton (R-MI) toured the Biomat Plasma Center in Kalamazoo, MI in honor of Primary Immune Deficiency Diseases Awareness Month April 5. Julie started her work with plasma centers as an IDF volunteer. The visit with Representative Upton, which was featured on the local news, resulted from her continued efforts to promote the work of plasma centers.

IDF Blogs include our community’s latest news and photos, allowing users to comment, submit content, and share posts:

IDF Community In Action:
www.idfcommunityinaction.org
Celebrate those who make a difference in the PIDD community.

IDF Policy Matters:
www.idfpolicymatters.org
Learn about critical advocacy efforts and public policy issues that directly impact patients.

IDF SCID Newborn Screening:
www.idfscidnewbornscreening.org
Follow the fight to have Severe Combined Immunodeficiency (SCID) newborn screening programs in all 50 states.

IDF Zebra Challenge:
www.idfchallenge.org
Be inspired by those who “Take the Zebra Challenge!” and fundraise for IDF. Read more about the Zebra Challenge on page 11.

IDF Plasma Centers Partners Program:
www.idfplasmacenterpartners.org
Discover how our plasma center partners—volunteers, plasma donors and participating plasma centers—play an integral role in our community.

To learn more about IDF Plasma Center Partners Program and IDF Donate & Donate, visit www.primaryimmune.org/idf-plasma-center-partners-program.
Nearly 50 volunteers from the Immune Deficiency Foundation community gathered on Capitol Hill March 22 for IDF's 2012 Advocacy Day. The volunteers, who had enthusiasm, spirit and readiness to "tackle the world," attended more than 90 meetings to make the case for the passage of HR 1845/S 960, the Medicare IVIG Access Act. As a result of current law, most Medicare beneficiaries with primary immunodeficiency diseases do not have access to home infusions of IVIG. The bill begins the process of fixing the home infusion benefit under Medicare Part B by paying for the equipment and nursing services necessary to have IVIG home infusions.

Not only is this legislation important for those individuals who are currently on Medicare, but it is also valuable for the larger IDF community as private insurance companies look to Medicare as an example for their health plans. In their meetings with Congressional offices, volunteer advocates stressed the IDF essential tenet of the importance of having access to all therapies in all sites of care. The day's meetings went very well with promises from several Congressional offices to co-sponsor HR 1845/ S 960. IDF volunteer advocates were terrific, and their stories certainly had a major effect on the people they met.

Do your part to advocate for the IDF community! Contact your Members of Congress and ask them to cosponsor and support the Medicare IVIG Access Act, HR 1845/S 960 through the IDF Action Alert System: www.primaryimmune.org/idf-advocacy-center/action-alerts.
Patient Resolves Insurance Fight Thanks to Persistence and IDF

Sheryl Vrieze faces a constant battle to maintain her health as a patient with a primary immunodeficiency disease. Little did she know that she would face a tough fight against her insurance company. Fortunately, with the help of the Immune Deficiency Foundation (IDF), Sheryl won.

Seventeen years ago, Sheryl was diagnosed with Common Variable Immunodeficiency (CVID). Within a month of her diagnosis, Sheryl started her intravenous immunoglobulin (IVIG) therapy. Upon starting her treatment, she experienced many adverse reactions including nausea, vomiting, diarrhea and body aches. After a year of changing therapies, Sheryl finally became stabilized on an IVIG product, and the adverse reactions ceased.

For more than 15 years, Sheryl has continued to receive the same IVIG therapy. In February 2012, Sheryl received a letter from Coventry Health Care in Georgia stating that she would have to switch IVIG therapy products on April 1, 2012. The health plan introduced a restrictive formulary—a list of drugs preferred by health insurance plans—forcing patients to switch therapies on which they are stabilized. This change could unjustifiably expose many, including Sheryl, to adverse reactions. The notice came only 30 days before the formulary went into effect leaving Sheryl and her healthcare providers with little time to react to the news.

Sheryl immediately began making phone calls to Coventry, her immunologist, her home infusion company and IDF. She was informed by Coventry that her doctor would have to write a letter proving her intolerance to any other drug. Sheryl’s doctor immediately became involved. After weeks of compiling information and communicating with Coventry, Sheryl was still scheduled to switch to the new preferred product. Therefore, she decided to put her treatment on hold—ultimately being forced to put her overall health and well being at risk.

IDF quickly stepped in to help and reached out to Coventry. As a result of Sheryl’s perseverance and IDF’s guidance, Sheryl was finally approved to stay on her current product. Coventry also assured Sheryl she would never be required to switch therapies again.

“I was in a fight to protect my health against a large insurer… They were uneducated about the therapy needs related to my specific disease—to them I was just a number,” said Sheryl, “I could not have won this battle without the support of the Immune Deficiency Foundation. They provided me with the strength in numbers that I needed to protect my health and my access to quality care.”

Hear Sheryl tell the story of her struggle with Coventry Health Care in her IDF Advocacy Channel video at www.primaryimmune.org/idf-advocacy-center.

What IDF Can Do for You

IDF wants to take your questions and hear your concerns! IDF staff are here to take patient inquiries and provide information. In fact, IDF fielded inquiries from more than 1,500 unique patients and addressed more than 2,700 different subjects in 2011. Contact IDF if you want to:

- Learn more about diagnosis and treatment.
- Request education materials.
- Locate a specialist.
- Connect with a Peer Support volunteer.
- Ask general insurance questions, e.g. co-pay assistance, denials, Medicare and Medicaid.
- Find information about manufacturers’ assistance programs.
- Learn what schools can do to accommodate children with PID.
- Inquire about handling employment discrimination.

IDF regularly addresses these topics and more. Contact us with your questions and concerns today: call 800.296.4433 (Monday - Friday 9 a.m. – 5 p.m. EST), complete the “ASK IDF” form at www.primaryimmune.org or email info@primaryimmune.org.

SCID Newborn Screening Update

This spring, Florida and Texas announced that the two states would soon begin screening for Severe Combined Immune Deficiency (SCID). In Florida, this came in the form of funding in the state budget, while in Texas the Department of State Health Services made the decision to include SCID testing on the state’s newborn screening panel.

SCID is a primary immunodeficiency disease. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive. It is imperative that newborn screening programs are established in all 50 states. Fortunately Florida and Texas can now be counted among those who will be screening newborns for SCID.

The Florida budget takes effect July 1, 2012, and advocates are hopeful that implementation can start at that time. The SCID newborn screening in Texas is anticipated to begin in September 2012.

The following states and territories currently include SCID in their newborn screening programs: California, Colorado, Connecticut, Delaware, Massachusetts, Michigan, Mississippi, Navajo Nation in Arizona and New Mexico, New York, Puerto Rico and Wisconsin.

Keep track of this important issue. Visit IDF’s SCID Newborn Screening blog: www.idfscidnewbornscreening.org. Comment, submit your news, and stay connected!
IDF President Marcia Boyle Testifies at FDA Public Hearing on Biosimilars

In an effort to voice concern on biosimilar pathways for patients with primary immunodeficiency diseases (PIDD), Marcia Boyle, president of the Immune Deficiency Foundation (IDF), offered oral testimony May 11 at the U.S. Food and Drug Administration (FDA) public hearing on draft guidance of biosimilar products.

Biosimilar regulatory changes are included in the recently passed Patient Protection and Affordable Care Act (Affordable Care Act). According to the FDA, the act creates an abbreviated licensure pathway for biological products that are demonstrated to be “biosimilar” to or “interchangeable” with an FDA-licensed biological product. A biological product may be demonstrated to be “biosimilar” if data show that, among other things, the product is “highly similar” to an already-approved biological product. The FDA assures healthcare professionals and consumers that they “will require licensed biosimilar and interchangeable biological products to meet the Agency’s exacting standards of safety and efficacy.”

Patients with primary immunodeficiency diseases have an enormous stake in exactly how the FDA changes the regulatory framework for biosimilars. Manufacturing changes, the composition of donor pools, and final formulations can impact patients’ tolerability, the infusion rate, and potential efficacy and safety of the product.

Currently, the FDA recognizes each immunoglobulin brand as unique—Ig products have no generic equivalents and are not clinically interchangeable. The FDA requires each drug to develop and complete an individual clinical trial protocol to receive licensure, even if it is from the same manufacturer. Current science cannot demonstrate that two products will provide the exact same clinical results for a large number of patients or that switching patients from one product to another will pose no additional risks. Patients can suffer adverse reactions to biosimilars that have not been adequately tested for safety and efficacy.

Marcia recommended that the following measures be incorporated in the FDA’s final biosimilar guidance documents:

1) Exempt immunoglobulin therapies from the biosimilars pathway;
2) Require clinical and nonclinical trials for biosimilars; and
3) Track and Trace and Automatic Substitution policies must reflect the safety of biosimilars and the sensitivities of patients with primary immunodeficiency diseases.

Marcia urged the FDA to follow the example set by the European Medicines Agency and exempt Ig therapy from the biosimilars pathway, or to at least require that biosimilar products undergo clinical trials to determine whether a proposed interchangeable therapy will offer patients the same clinical outcome. However, at minimum, given the unique properties of biosimilars, and immunoglobulin therapies in particular, she said that the focus should be on making sure that the biosimilars approval process meets the same strict criteria required for current manufacturers.

To read Marcia Boyle’s entire Biosimilars Testimony, go to www.primaryimmune.org/idf-advocacy-center.
Preparation is underway for the THINK ZEBRA! Silent Auction at the IDF 2013 National Conference in Baltimore, MD. Some of the most fabulous auction items require a good amount of planning, like donating a getaway package, airline tickets, a week at a vacation home, tickets to a professional sporting event, or autographed memorabilia. Start thinking about how you can secure these special items for IDF now!

Perhaps you have a connection with a popular celebrity, like an actor, athlete or other public figure. Many celebrities are very generous if they are contacted in advance. In 2011, just two auction items that involved meeting celebrities raised $4,500 for IDF! Please note that celebrities do not need to appear in Baltimore, and IDF can offer “Meet a Celebrity” packages through a charity website anywhere in the country. Help us make the THINK ZEBRA! Silent Auction a tremendous success with extraordinary items! To discuss your ideas and arrange your donation, contact IDF at 800.296.4433 or idf@primaryimmune.org.

IDF Retreat
Houston, TX - September 7-9

There is still time to register for the IDF Retreat in Houston, TX – September 7-9, 2012. IDF Retreats are for everyone in the primary immunodeficiency community – patients, parents, siblings, children, teens and partners. Come connect with the IDF Community and have some fun while developing better approaches to living with primary immunodeficiency.

Space is limited and will be assigned on a first-come, first-served basis.

Patients and Families Rates

- **Individual Registration** - $115 (1 person, includes one hotel room)
- **Family Registration** - $195 (2-4 persons, includes one hotel room)
- **Family Registration** - $325 (5-8 persons, includes two hotel rooms)

A limited number of scholarships to cover registration fees only are available based on financial need.

For more information about scholarship and general retreat information, please contact IDF at 800.296.4433 or retreats@primaryimmune.org.

The IDF Retreats are generously supported by charitable donations from Baxter Healthcare Corporation, CSL Behring, Grifols, IgG America/ASD Healthcare/US Bioservices, Octapharma and Sigma-Tau Pharmaceuticals.

IDF 2013 National Conference
THINK ZEBRA! Silent Auction
Plan for Fabulous Donations Now!

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What Can You Do in 4 Minutes or Less?

- Make a pot of coffee?
- Unload the dishwasher?
- Take out the trash?

How about using those 4 minutes to take charge of your health information with the IDF eHealthRecord, an electronic personal health record custom designed for the primary immunodeficiency disease community?

Watch IDF’s “4 Minutes or Less” videos to learn how to:

- Keep an infusion log
- Create an “In Case of Emergency” (ICE) Report

In these videos, IDF staff members will show you how simple the IDF eHealthRecord can be—how effortless keeping track of your care can be. The IDF eHealthRecord is a free one-of-a-kind electronic personal health record developed for individuals and families living with primary immunodeficiency diseases that allows patients and caregivers to manage their medical information online.

Watch 4 Minutes or Less!

Visit www.primaryimmune.org and click on eHealthRecord to view the “4 Minutes or Less” videos. IDF staff members are available to answer questions, provide technical support, or just walk you through the process. Contact us: 800.296.4433 (Monday-Friday, 9 a.m.-5 p.m. EST) or info@idfehealthrecord.org.

eHealthRecord
Immune Deficiency Foundation
Thromboembolic events are a small but definite risk in patients receiving immune globulin (IG) products. This risk may be increased for patients receiving specific lots of subcutaneous or intravenous immunoglobulins. About 75% of the events are arterial, such as a heart attack or stroke, usually occurring within hours or days after an infusion. Less common is venous thrombosis (25%) such as a blood clot in the leg leading to pulmonary embolism or deep vein thrombosis, usually occurring days or weeks after an infusion.

The risk for immunodeficient patients receiving standard doses of IG products (300-600 mg/kg monthly) is less than that for patients receiving high immunomodulatory doses (e.g. 1000 mg/kg/day or greater) for neurologic disorders (e.g. polyneuritis) or autoimmune disorders. Further, the subcutaneous or intramuscular route is probably less likely to cause thrombosis than the intravenous route.

The first case of thrombosis due to IGIV was reported in 1986 by Woodruff et al. Since that time, increasing numbers of such events have been reported. The exact incidence is not known but may be as high as 1% in certain high risk situations. Thrombotic events have been reported for all products, to a greater or lesser extent. A recent publication from the U.S. Food and Drug Administration (FDA) details the thrombotic events in 11,785 patients from 2008-2010 exposed to various immune globulin products. There were 122 thrombotic events recorded, and risk factors and products involved were identified. (Daniel et al, 2012)

The FDA held a two-day meeting in Rockville, MD in May 2011 to address this problem. This was attended by 300 government officials, manufacturers, pharmacists, coagulation experts and clinicians. Marcia Boyle and I represented the Immune Deficiency Foundation at the meeting.

Risk factors for thrombosis include patient factors, infusion factors and product factors (Table 1). More than one risk factor multiplies the likelihood of such an event.

The FDA is evaluating if changes in product labeling are needed to emphasize the risk of thrombosis, including risk factors and suggestions on how to minimize risks for some patients. So far, however, there is no black box warning unlike that issued for IGIV associated with renal dysfunction, which can include acute renal failure, osmotic nephrosis and death, particularly with IGIV products containing sucrose.

Since 2009, FDA and manufacturers identified certain lots of IGIV, IGIM and SCIG with increased procoagulant activity. These lots contain coagulation factors that promote blood clotting. The factors are present in the source plasma and are not removed during manufacture. They are identified by an assay termed the thrombin generation test. (Thrombin causes circulating fibrinogen to form a fibrin clot.) The chief (but not the only) procoagulant factor is activated coagulation Factor XI (FXIa).

Table 1 - Risk Factors for Thromboembolism

<table>
<thead>
<tr>
<th>Product Factors</th>
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</thead>
<tbody>
<tr>
<td>Presence of procoagulant activity</td>
</tr>
<tr>
<td>Concentration and osmolarity have been theorized as causes but are unproven</td>
</tr>
<tr>
<td>Other causes may exist, and this is a subject of scientific study</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Infusion Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large dose</td>
</tr>
<tr>
<td>Rapid dose infusion</td>
</tr>
<tr>
<td>No pre-infusion or post-infusion hydration</td>
</tr>
<tr>
<td>First infusion</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older age</td>
</tr>
<tr>
<td>Immobility/air travel</td>
</tr>
<tr>
<td>Hypertension</td>
</tr>
<tr>
<td>Present or past cardiovascular disease</td>
</tr>
<tr>
<td>Diabetes</td>
</tr>
<tr>
<td>High lipids/cholesterol</td>
</tr>
<tr>
<td>Elevated serum proteins/gammopathy</td>
</tr>
<tr>
<td>Smoking</td>
</tr>
<tr>
<td>Prior thrombosis</td>
</tr>
<tr>
<td>Estrogen use</td>
</tr>
<tr>
<td>Hereditary hypercoagulable states (Factor V Leiden or prothrombin mutations, Protein C, S or antithrombin III deficiencies)</td>
</tr>
<tr>
<td>Permanent indwelling venous catheter (i.e. Portacath)</td>
</tr>
</tbody>
</table>

The FDA is working with companies towards the goal of testing all product lots for procoagulant activity prior to release. Octagam was temporarily withdrawn from the American market in 2010 because of procoagulant activity but, after manufacturing changes, is now back on the market. Vivaglobin for subcutaneous use was found to have increased levels of procoagulant activity and is no longer distributed in the U.S.

On March 23, 2012, it was announced that GamaSTAN S/D a 16% product licensed for hepatitis A, measles, varicella and rubella prophylaxis and for the treatment of immunoglobulin deficiency may have procoagulant activity. I believe immunodeficient patients should not receive GamaSTAN for replacement therapy either by the intramuscular or subcutaneous route because of the large volume and repetitive doses needed.

The FDA gathers reports of thrombotic and other adverse events from IG use via the manufacturers, analysis of insurance claims and direct reports from physicians, to find out whether a product has unusually high rates of events and to identify specific lots that have been associated with a thrombotic event, for study.
Patients/parents should:
1) Tell your doctor if you have any risk factors for thromboembolism. (Table 1)
2) Keep a record of the date, brand, lot number dose and side effects of each infusion.*
3) Notify the manufacturer and/or FDA if you or your child has a thromboembolic event. Please include the lot number and product brand.
4) Do not switch IG product brand if one has been used successfully in the past.

Doctors/nurses should:
1) Know the risk factors for thromboembolism.
2) Consider the precautions shown in Table 2 to minimize these reactions.
3) Record the date, dose, lot number and side effects of each infusion.
4) Report adverse events, including the lot number and product brand.
5) Avoid changing brands if one brand has been well tolerated.

IDF, through their communications with patients, family members and medical personnel, will keep you informed.

*Record all your health information in one place at www.idfehealthrecord.org.

Table 2 - Minimizing risk of thrombosis for IGIV infusions

<table>
<thead>
<tr>
<th>Pre/post-infusion hydration.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slow infusion rate, e.g. 50mg/kg for first hour, 100 mg/kg hr, thereafter.</td>
</tr>
<tr>
<td>Avoid “as tolerated” dose escalation.</td>
</tr>
<tr>
<td>Consider premedication with ASA or heparin/enoxaparin in high risk patients (see reference 13).</td>
</tr>
<tr>
<td>Testing for hypercoagulable tests/viscosity/dysproteinemias.</td>
</tr>
<tr>
<td>Doppler tests for clots in bedridden patients.</td>
</tr>
</tbody>
</table>

References
14) Daniel GW, Meni M, Sridhar, G et al Immune globulins and thrombotic adverse events as recorded in a large administrative database in 2008 through 2010 Transfusion 2012 (in press).
IDF Arcade Reaches Russia

IDF Arcade is a great place for kids—apparently even for kids in Russia! Violetta Kozhereva of the Sunflower Charity Foundation, a Russian charity foundation for patients with primary immunodeficiency diseases, recently reached out to IDF to compliment the children’s games in the IDF Arcade at www.primaryimmune.org.

“IDF worked out a great section for kids,” says Violetta, “The games are a lot of fun, and some of our patients played them at the hospital.”

Our Immune System, IDF’s beloved storybook for children with primary immunodeficiency diseases, was taken to a completely new level in the IDF Arcade, bringing the characters to life in interactive games that combine education and entertainment to teach young children about their disease. Games include Whack-A-Germ, Phagocyte Force-The Power to Devour and Jigsaw Puzzler. The IDF Arcade was made possible by the support of IgG America, ASD Healthcare and US Bioservices.

IDF Kids Connection, the section of www.primaryimmune.org dedicated to kids, features the IDF Arcade as well as Our Immune System, IDF School Guide, links to kids merchandise on CaféPress and more. Thousands of children, teens and even adults have enjoyed the IDF Arcade, and now it has gone international!

The Sunflower Charity Foundation, a member of IPOPI - International Patient Organisation for Primary Immunodeficiencies - is taking advantage of the IDF Arcade and more of IDF’s resources. Sunflower received permission from IDF to reprint Our Immune System in Russian. In addition, the foundation has created its own fundraising campaign inspired by the IDF Blue Jeans for Healthy Genes program.

“We wanted to ask IDF to translate IDF Blue Jeans for Healthy Genes in Russian but could not save the play of words with a literal translation,” explains Violetta. Therefore the organization launched “Bright Day – More Color for Immunity,” an activity in which people dress in bright colors and, by bright appearance and personal contributions, demonstrate support and assistance to those whose life is devoid of natural colors of life – children with primary immunodeficiency diseases. The organization conducted its first “Bright Day” April 26, at the end of World Primary Immunodeficiencies Week.

“Looking at the lifeline of IDF, we are in the very beginning of the road,” explains Violetta, “In Russia, we have a bit more than 1,500 patients diagnosed compared to more than 250,000 in the U.S.” Sunflower Charity Foundation, however, is making wonderful progress. Last year the foundation held its first unity congress with experts and patients.

The IDF Arcade has helped connect two growing patient organizations, strengthening the international community of families living with primary immunodeficiency diseases! To join in the fun, go to www.primaryimmune.org/patients-and-families/idf-kids-connection.
Take the Zebra Challenge!

What is the Zebra Challenge? IDF challenges everyone to join in our fundraising efforts by creating personal fundraisers and teaching the world about “ZEBRAS.” In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras,” and they are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. Sometimes, however, physicians need to look for a zebra. Patients with primary immunodeficiency diseases are the zebras of the medical world. Please help IDF and teach the world about “ZEBRAS” while raising funds!

There are many ways to Take the Zebra Challenge! Find them in the new section of IDF’s website: www.primaryimmune.org/take-the-zebra-challenge:

- Create a personal fundraising page. Through the page you can tell your story, add photos or videos, and invite your family and friends to donate.
- Host a special fundraising event. We show you how to get started.
- Educate family and friends while raising funds with our THINK ZEBRA! program.
- Make a gift directly to IDF.
- Purchase items from our Café Press shop.
- Order the new IDF Zebra Ribbon Pin.
- Check out the new IDF Zebra Challenge blog (www.idfchallenge.org) that celebrates all members of the primary immunodeficiency community who took the Zebra Challenge and raised funds for IDF.

Take the Zebra Challenge today!

One Family TAKES THE ZEBRA CHALLENGE, Raises More Than $1,500

The Huot Family of Philadelphia “took the Zebra Challenge” and reached out to their family, friends and coworkers because of their own little zebra, three-year-old son Zak. Heather Huot, Zak’s mom, started a personal fundraising page and began sharing her family’s story. To date they have raised more than $1,500, exceeding their $1,000 goal.

At 18 months, doctors diagnosed Zak as failure to thrive, and at age three—after a year and a half of testing—he was diagnosed with CVID. Zak now receives monthly IVIG at home and attends preschool. He has not had any serious illnesses or infections since starting IVIG, and for that the family is so grateful.

“In the year that Zak has been diagnosed, IDF has been an incredible resource and support for us and we felt we needed to do something to give back from our little corner of the world,” explains Heather.

And that little corner of the world is generous, helping the Huots surpass their $1,000 goal with more than $1,500 raised! To really make a difference, Heather put a link to their fundraising page on facebook multiple times and sent regular e-mails to family, friends and coworkers. She believes direct e-mails have been the most effective because she can share updates and encourage giving.

“My husband and I have been overwhelmed by the outpouring of support by our family and friends,” says Heather. “It not only makes us feel that we were successful in supporting IDF, but also really touches our hearts and let us know how many people are behind us every day. It has also inspired us to raise the bar next year and come up with additional ways to raise money for IDF in the years to come.”

IDF is tremendously grateful for families like the Huots. Thank you to all those who have donated to IDF!

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Have you ever thought about including IDF in your estate planning? There are many untraditional ways you and family members can support IDF in the future, including bequests, life insurance policies, trusts or annuities. A little preparation now can make a huge difference for IDF in the years to come. If you would like more information, contact IDF at 800.296.4433 or idf@primaryimmune.org.
For an Updated IDF Calendar of Events, Visit www.primaryimmune.org/event-calendar.

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