A Mother’s Fight for Her Son

Natalie Cheek, Columbia, Missouri resident and mother of vibrant 5 year-old boy, Kalum, is worried that her child’s well being and health are at risk because of a business decision by her son’s insurance company, Coventry Health Care.

Little Kalum Cheek began getting very sick repeatedly when he was six months old. As infections and sicknesses progressed, Natalie began to realize that this was not normal.

“I told his physician over and over again that something was wrong, but over the next six months, I was ignored as his constant colds, flu, and unknown viruses turned into battles with pneumonia,” says Natalie.

Natalie felt completely helpless, watching her infant child fight a losing battle—knowing she was unable to protect him.

A few days before his first birthday, Kalum was hospitalized for the third time. At this point, the doctors began to consider that Natalie’s motherly intuition might be on to something. The doctors broadened their tests and discovered a defect in his immune system. Kalum’s gamma globulin levels were basically non-existent.

The doctors and specialist were finally able to diagnose Kalum as having X-Linked Agammaglobulinemia (XLA), which is also known as Bruton’s Disease, a rare primary immunodeficiency disease (PIDD).

Finally, Natalie and the team of doctors knew how to protect him. Kalum began receiving immunoglobulin infusions regularly. Over time, his lungs, which were severely damaged due to pneumonia, began to heal.

Every three weeks, Kalum undergoes intravenous immunoglobulin replacement (IVIG) therapy, so his body can fight off infections.

Effective December 1, 2012, Coventry Health Care of Missouri, Pennsylvania and Illinois, introduced a restrictive formulary—a list of drugs preferred by health insurance plans—that has begun negatively impacting patients living with primary immunodeficiency diseases (PIDD), forcing patients to switch therapies on which they are stabilized and unjustifiably exposing them to adverse reactions.

Coventry Health Care’s plan eliminates the important, specialized role physicians have in prescribing the best intravenous immune globulin replacement (IVIG) therapy product for each patient living with PIDD.

When Natalie learned that her insurance company, Coventry Health Care of Missouri had made the decision to mandate a specific formulary for IVIG treatments, she knew that she needed to make her voice heard on behalf of her son.

“I have heard nightmarish stories about those living with PIDD that have to change therapies and experience adverse reactions,” said Natalie. “A five year-old should not have to endure this. My son’s lungs have finally recovered. Kalum’s such such a happy-go-lucky little boy, the last thing I want to put him through is having to adjust to a therapy that may not be a good fit for him.”

Natalie has spent the last four years ensuring that her son is stabilized on his medication and won’t let Coventry’s recent formulary change affect her son without a fight.

“I have seen my baby go through so much pain, I will do anything to make sure he never has to suffer unnecessarily again,” continues Natalie.

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For existing patients who have been stabilized on a specific, physician-prescribed Ig product, the stakes may be very high. Based on the medical literature and according to the IDF Medical Advisory Committee, about one-third of all adverse reactions to immunoglobulin infusions occur in the context of changing products.

Natalie feels that Coventry Health Care of Missouri sees their policyholders as just numbers in a system.

"My son is not just a number," says Natalie emphatically. "He is a unique person whose body is built differently than anyone else’s. How can Coventry Health Care of Missouri expect one Ig product to work for everyone, knowing full well that painful reactions to those whose bodies aren’t compatible with it are in inevitable?"

Natalie refuses to stand by as Coventry Health Care of Missouri jeopardizes her son’s health.

"My priority is that my son is healthy, and it is my goal to keep him that way," continues Natalie.

Natalie is in the process of discussing the implications of Coventry’s formulary changes with Kalum’s doctor.

"My son’s doctor wasn’t even aware of the changes," continued Natalie. "I’m doing all my own research because I need to know what my next step will be if my son’s forced to switch his therapy."

Tearfully, she continues, “At a time when all my little boy should be worried about is what ‘superhero of the day’ he’ll be, he may have to endure unnecessary pain and suffering all because one company wants to increase profits.”

Tearfully, she continues, “At a time when all my little boy should be worried about is what ‘superhero of the day’ he’ll be, he may have to endure unnecessary pain and suffering all because one company wants to increase profits.”

Natalie’s hope is that by telling her son’s story, countless others will learn of this formulary change and advocate for change.

If you or someone you know has Coventry Health Care as a health insurer, please contact us at: 1-800-296-4433. Visit our website, http://insurersarenotdoctors.org to learn more about how your voice can be heard to stop these unnecessary formularies from jeopardizing the health of those living with PIDD.
What is the Coventry Health Care Policy Doing to Patients who Require Ig Replacement Therapy?

Effective December 1, 2011, Coventry Health Care in Pennsylvania (HealthAmerica), Missouri, and Illinois introduced a restrictive formulary which affects patients with primary immunodeficiency diseases (PIDD) who use immunoglobulin replacement (Ig) therapy. A formulary, by definition, will curtail access to Ig product selection, mandating patients be switched to use Coventry’s one preferred product, which has not been used extensively in the United States. This includes not only patients who have been receiving another intravenous immunoglobulin replacement therapy (IVIG) but also those who have been receiving a subcutaneous immunoglobulin replacement therapy (SCIG), forcing both to use the new preferred IVIG product. There are important reasons for physicians to prescribe specific Ig products, as well as the route of administration. The IDF Medical Advisory Committee calls this new policy an unjustifiable safety risk that disregards the unique needs of patients.

The Immune Deficiency Foundation (IDF) and its medical advisors are opposed to Coventry Health Care’s policy for the following reasons:

This policy interferes with a physician’s ability to select the most appropriate Ig therapy for each patient and further requires that a patient risk experiencing an adverse infusion reaction while switching, based on an insurance formulary rather than on a medical reason.

This mandate will disrupt patient care by making an individual switch to a new therapy, even when their current therapy is successful. By exposing all patients to a restrictive fail-first formulary policy, insurers are mandating that some of these often-frail patients will need to experience potentially life-threatening adverse reactions with no medical justification for immediately available if needed.

This policy is already impacting patient care. There is a physician in Pennsylvania treating a patient with PIDD who is a Coventry member. The patient was stabilized for 2 years with no issues at all on a different Ig product. Following the implementation of this formulary, the patient was forced to switch to the new preferred product. Within an hour of the infusion, the patient experienced partial face paralysis and a respiratory issue. Both issues were temporary, but there was no reason that this patient should have had to go through that experience. This is just the first case IDF has become aware of, there will inevitably be more patients put at risk if this policy continues.

For more information about Coventry Health Care’s Ig policy and the IDF campaign against this restrictive formulary, please visit www.InsurersAreNotDoctors.org. This policy will likely be implemented throughout the U.S., so please contact IDF if you are a patient who will be impacted by this insurance policy.
IDF: 2011 In Numbers

In 2011, we celebrated 30 Years of IDF! It was a remarkable year, filled with initiatives and programming to meet our mission statement to improve diagnosis, treatment and quality of life for persons with primary immunodeficiency diseases. As we begin a new year, it is always helpful to evaluate the impact IDF had while working on behalf of our community in 2011.

In 2011, nearly 12,675 patients and healthcare professionals attended more than 136 educational presentations in 95 cities in 34 states. This includes the 1,010 strong that participated in the IDF 2011 National Conference in Phoenix. Among IDF’s educational programs for patients were Education and Get-Connected Meetings, Operation Outreach programs, Teen Escapes and Health Fairs.

Our medical outreach programs included IDF exhibits at four medical conferences as well as ten LeBien Visiting Professor Programs. Over 109,500 IDF educational materials were distributed in response to requests from patients and healthcare professionals.

A new online continuing education course for nurses, Primary Immunodeficiency Diseases and Immunoglobulin Therapy, was introduced in July and during 2011, 564 nurses registered for this free, five credit course.

The IDF eHealthRecord, a one of a kind electronic personal health record specifically developed for individuals and families living with primary immunodeficiency diseases, was launched in July. This online tool helps patients take charge of their health information and management in one place and in 2011, 355 health records were created.

Our volunteer network continues to further IDF’s mission. They helped spread awareness by distributing thousands of pieces of educational materials and spoke to approximately 4,250 people during 70 visits to Plasma Centers. Peer support volunteers offered encouragement and advice for 162 patients or family members living with primary immunodeficiency who requested to talk to someone who “has been there and understands.”

The Foundation strives – through public policy action and advocacy – to be a strong and influential voice on the issues affecting our community and our quality of life. Last year, IDF’s public policy efforts resulted in an Advocacy Day on Capitol Hill that saw our volunteers visit 91 offices to meet with their members of Congress about issues important to the primary immunodeficiency community. Eleven separate Federal and State level calls to actions were sent through the IDF Action Alert system generating 5,679 letters to Policy Makers. Volunteers working on the SCID newborn screening campaign were active in 30 states in 2011, including giving testimony to the legislature or advisory committees in 16 states.

IDF’s patient advocacy services helped fill the need for over 3,600 requests from patients and families seeking education, information and assistance. There was a considerable increase for requests for patient education, peer support, medical or treatment questions and in particular, locating a specialist in 2011. In fact, compared to 2010 when there were 173 requests to find a physician, that number jumped to 560 in 2011, more than tripling the number of requests!

IDF national patient surveys provide crucial insight into the personal impact of primary immunodeficiencies and help the Foundation develop policies for improved diagnosis and treatment. In 2011, we saw more than 3,400 patients participate in seven IDF surveys.

IDF communications enlighten and inform our community with our newsletter, IDF ADVOCATE, three times a year (circulation of 22,000), and a monthly e-newsletter, Primary Immune Tribune, (reaching over 13,400). Our new website was launched in June and the performance boasts an 18% increase in visits with the average time spent on the site swelling almost 32%. Our social networking sites, IDF Friends and IDF Common Ground, continue to grow with almost 3,000 members. Add to that four active blogs and the new IDF TV as a hub for all our videos that have been watched 83,353 times.

The United States Immunodeficiency Network, USIDNET, a program of IDF, is a network of leading immunologists who have joined together to advance knowledge in the field of primary immunodeficiencies. A key component is the Patient Registry, which is comprised of patients who are affected by primary immunodeficiency disorders. In 2011, the number of patients participating in the registry surpassed the 2,884 mark.

Adding it all up - 2011 was a productive year!

Join us in 2012 and help IDF provide the myriad of services, education, information and advocacy that our community needs and so richly deserves.

Checkout the 30 Years of IDF timeline at http://primaryimmune.org/about/30-years-of-IDF
April is Primary Immunodeficiency Awareness Month! So this April, join with the IDF, in partnership with World PI Week, celebrated April 22 to 29, to promote awareness of primary immunodeficiency diseases in your community.

If you live with primary immunodeficiency diseases (PIDD), or you have a significant relationship with someone who is affected, you know how important it is to raise awareness and understanding about these diseases. This is a perfect opportunity to educate and inform people about PIDD and hopefully, this knowledge will lead to early diagnosis and appropriate treatment.

To get you started, below is a list of ways you can help increase awareness of PIDD. Have fun, be creative, and get the word out!

**Distribute Educational Information**

One of the easiest ways to promote awareness is by spreading the word in your community. You can download or order posters, information cards and IDF publications to distribute to libraries, doctor’s offices, infusion centers, home healthcare companies, places of worship, schools and other civic organizations.

Download promotional materials at www.primaryimmune.org, and order copies by contacting IDF at idf@primaryimmune.org, or 800-296-4433.

**Contact the Media**

If you are interested in telling your story to the local media, visit our website and download our Press Kit at www.primaryimmune.org. The kit includes steps on how to go about contacting the media, sample letters and press releases, FAQs about PIDD and other helpful information to use when reaching out to your local media.

**Take Action and Advocate**

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

**Host an Event**

Consider hosting an event such as a bowl-a-thon, bake sale or trivia night to raise funds and spread awareness. By getting a little creative, you can personalize your event in your own special way and make it a success.

**THINK ZEBRA! Fundraising Kits**

Our fundraising kits are available to help you create a fundraising plan and get started raising funds and awareness of primary immunodeficiency diseases, while also helping to save lives! Money raised will help fund patient and physician education and awareness. Download a PDF version of the THINK ZEBRA! Fundraising Kit at www.primaryimmune.org or you can order kits by contacting IDF at idf@primaryimmune.org, or 800-296-4433.

**Tell Us What You Did!**

No matter how you decide to promote Primary Immunodeficiency Awareness Month, make sure you tell us what you did! Submit stories and pictures for inclusion in the IDF Community in Action blog http://idfcommunityinaction.org and the IDF ADVOCATE newsletter to idf@primaryimmune.org.
April is Primary Immunodeficiency Awareness Month, and the Immune Deficiency Foundation wants everyone to THINK ZEBRA!

Why does the Immune Deficiency Foundation say, “THINK ZEBRA!”?

When doctors go to school they learn the saying, “When you hear hoof beats, think horses, not zebras.” This means, when doctors treat people they should think about common illnesses, not unusual ones.

However, sometimes people get sick a lot, their illness doesn’t get better or they have an unusual infection. When this happens, doctors should wonder whether the person might be a zebra with an unusual condition, like primary immunodeficiency disease, and not a horse with a common infection.

People with primary immunodeficiency diseases are the zebras of the medical world! Help IDF teach everyone to THINK ZEBRA!

“When you hear hoof beats, think zebras, not horses.”

IDF has created Zebra Zone, a special place for youth to show their stripes and Think Zebra! We hope you will join us for some fun! Visit www.primaryimmune.org/zebra-zone and visit our IDF Kids Connection section at http://primaryimmune.org/patients-and-families/idf-kids-connection

**Zebra Roundup** (Circle the zebras that are the same to make a herd)

**Fun Fact:** Every zebra has a unique pattern of stripes, just as every person has a unique pattern of fingerprints.

**Zebra Jokes!**

What is the silliest name you can give a zebra? — *Spot*

If a four-legged animal a quadruped and a two-legged animal is a biped, what’s a zebra? — *Stri-ped*

What’s black and white and noisy? — *A zebra with a set of drums*

Do you have a zebra joke for IDF? Send it to idf@primaryimmune.org and we’ll add it to the IDF Zebra Zone for others to enjoy! at www.primaryimmune.org

**PIDD Unscramble Match**

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<th>abrze</th>
<th>rodtcos</th>
<th>mpirray</th>
<th>fionnicte</th>
<th>eimnum</th>
<th>ciienfeyd</th>
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**Heathy Match**

Eat healthy | exercise
Stay fit through | foods
Before you eat, wash your | teeth
Brush your | hands
Get plenty of | cough
Cover your | rest
Show your stripes, and join the herd at the IDF Zebra Zone!

Color the zebra. Send a scanned copy to IDF at idf@primaryimmune.org, or mail it to Immune Deficiency Foundation, 40 W. Chesapeake Ave., Suite 308, Towson, MD 21204. IDF will add your zebra picture to the Zebra Zone on the IDF website.

First Name: _______________________________ State: _________ Age: _______
Physicians want to understand patients who have primary immunodeficiencies and you can help. If you want to be involved in this project, you can do two simple things:

- Sign up for the USIDNET Patient Registry
- Complete the Quality of Life Survey

The United States Immunodeficiency Network (USIDNET) is a research consortium established to advance scientific research in the field of primary immunodeficiency disorders. A focus area of this initiative is the Patient Disease Registry which is collecting data on patients with primary immunodeficiency diseases. After a patient signs consent for data to be entered, this information is combined with thousands of others to provide a comprehensive database so that questions can be answered. The identity of enrolled patients is kept strictly confidential.

However, even though you or a loved one may have a primary immunodeficiency, there is much more that defines you than the disease. You are also a whole person with a variety of needs and feelings. The USIDNET Registry takes a holistic approach to gathering all the information we can, to better understand what happens to patients experiencing different kinds of treatment and types of issues. The Quality of Life survey focuses on questions about everyday living and general behavior and well-being. It is for all patients and parents of patients.

According to Charlotte Cunningham-Rundles, MD, PhD, The David S. Gottesman Professor at the Immunology Institute at Mount Sinai School of Medicine in New York, as well as the Principal Investigator for the USIDNET Project, “It is exciting to see patients take the initiative and share their experiences through this survey. Results from the Quality of Life survey help to provide a total picture of the life of a person, including their inner thoughts and what it is like to live with a primary immunodeficiency. Participation of patients will help us understand what happens with different kinds of treatment and what types of problems they might be having.”

Once patients consent to become part of the USIDNET Patient Registry they can complete the Quality of Life Survey. The information is deidentified so patients are able to be open and honest about their answers to the survey questions. A password is required to gain access to the survey. Submit a written request to the USIDNET Registry Manager and you will receive a password. Instructions are on the website under the patient tab on www.usidnet.org.

For more information go to the USIDNET website: www.usidnet.org or call the Registry Manager at 866-939-7568.

The United States Immunodeficiency Network, (USIDNET) a program of the Immune Deficiency Foundation (IDF) is funded in part by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institutes of Health (NIH) an agency of the Department of Health & Human Services. NIAID supports research to advance the understanding of transplantation and to prevent, diagnose and treat infections and Immune-mediated illnesses. USIDNET administrative support is provided by IDF.

IDF: Patients with PIDD have unique needs in Health Care Reform

The Patient Protection and Affordable Care Act, health care reform legislation enacted in March 2010, included many provisions and mandates that are continuing to be understood and debated as the law is implemented. One provision created the Patient-Centered Outcomes Research Institute to provide for comparative effectiveness research in the United States. It is designed to form health care decisions by providing evidence on the effectiveness, benefits and harms of different treatment. IDF wrote the article, Comparative effectiveness research in the United States and primary immunodeficiency diseases, warning against the possibility of using comparative effectiveness research to only reduce costs rather than focus on quality of care. In the article, IDF addresses the importance of ensuring that the unique medical concerns of patients with primary immunodeficiency diseases are not overlooked. Instead, these concerns should be part of an overall healthcare emphasis on the unique condition and treatment of the individual patient.

To view the entire article visit:

This article was published in Pharmaceuticals Policy and Law 13 (2011) 183–191.
In July 2011, Patient Services, Inc. (PSI) started a pilot co-payment assistance program for primary immunodeficiency diseases. Through PSI's research, they found that there are people and families in the PIDD community struggling to afford their co-payments for treatments. Together, the Immune Deficiency Foundation and PSI are making a unified effort to reach out to people and families who have a financial need for co-payment assistance. If you previously applied for this assistance and were denied based on income, we encourage you to re-apply as PSI's eligibility requirements for this program have recently changed.

In addition to this new pilot co-payment assistance program, PSI offers a health insurance premium assistance program. Qualified patients may select premium or co-payment assistance, whichever is most needed. Please note that applicants are only eligible for one or the other at this time. To determine your financial eligibility for assistance, please log on to the PSI website at www.patientservicesinc.org and select the Income Prescreening Tool. The tool allows you to prescreen financial eligibility and provides a link to complete an online application. If approved for assistance, PSI may be able to assist you with your health insurance premiums or co-payments for one year.

Contact PSI to see if they can help you! Visit them online at www.patientservicesinc.org or call one of their Patient Services Representatives at 1.800.366.7741.

IDF Retreats are for everyone in the primary immunodeficiency community – patients, parents, siblings, children and partners. Whether you are newly diagnosed or have been living with a primary immunodeficiency disease for years, IDF Retreats offer an opportunity to connect with others to learn more about dealing with your disease. Leading physicians and healthcare professionals will present the latest information about the treatment and management of primary immunodeficiencies. Life management and everyday concerns will be featured in panel discussions led by experts in their fields. The youth and teen programs offer both education and fun, and are designed to help the younger members of our community better manage their diseases.

Perhaps, most importantly, these weekend gatherings offer an atmosphere to build relationships with others who share common experiences, therapies and feelings. So, come connect with the IDF Community and have some fun while developing better approaches to live with primary immunodeficiency.

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

For Youth
- Teen Escape (13 - 18 years) This activity-packed, fun-filled program is designed for teens to promote friendship, build leadership skills, develop coping skills and learn about primary immunodeficiency diseases from medical experts.
- Kids Club (5 - 9 years) and ‘Tween Scene (10 - 12 years) These groups will enjoy crafts, games, and learn about their immune system and how to take care of themselves in between other fun activities.
- Childcare (6 months - 4 years) is available from KiddieCorp, an organization that provides high-quality services and age appropriate activities for children.
FDA Approves U.S. Market Return for Octagam Following Octapharma’s Implementation of Enhanced Safety Measures

The U.S. Food and Drug Administration (FDA) yesterday cleared the way for the U.S. market return of octagam® [Immune Globulin Intravenous (human)] 5% Liquid Preparation, the Octapharma USA product used to treat disorders of the immune system.

In August 2010, Octapharma initiated a voluntary market withdrawal of selected lots of octagam® 5% in the U.S. in response to an observed increase in thromboembolic events (TEEs) and subsequently expanded the voluntary withdrawal to all lots of octagam®, illustrating the biopharmaceutical company’s preference to exercise the highest level of patient safety. Over the last year, Octapharma has collaborated with the FDA in analyzing the issue of procoagulant activity in industry-wide immune globulin products, which in some cases lead to TEEs in many IVIG products on the market today.

The FDA approval was based on changes Octapharma has made in the octagam® 5% manufacturing process and the company’s decision to implement a quality control test on every batch of the product that is released to the marketplace. Additionally, Octapharma will implement post-marketing studies to ensure product safety.

Excerpted from Octapharma new release April 11, 2011

Kedrion Biopharma, Inc. Launches Gammaked in the U.S. Market

Kedrion Biopharma (www.kedrionusa.com) today announced the approval and U.S. availability of Gammaked®, a ready-to-use sterile solution of human immune globulin proteins for intravenous and subcutaneous (primary Immunodeficiency only) administration. Kedrion, a biopharmaceutical company that develops, manufactures and distributes human plasma-derived medicines, has entered into an agreement with Grifols, SA to manufacture Gammaked for the next seven years. As part of its ongoing expansion in the United States, Kedrion will begin distribution of Gammaked on August 3, 2011 through designated channel partners.

Gammaked is an immune globulin human injection, 10 percent liquid indicated for treatment of:

- Primary Immunodeficiency (PI)
- Idiopathic Thrombocytopenic Purpura (ITP)
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Excerpted from Kedrion USA new release August 2, 2011

CSL Behring Awards Lead Grant to Patient Organizations to Educate Constituents on State Insurance Exchanges

CSL Behring announced today that it has awarded a $40,000 advocacy grant to the American Plasma Users Coalition (A-PLUS) through its Local Empowerment for Advocacy Development (LEAD) program. LEAD grants support the grassroots advocacy efforts of organizations that help people who use plasma-derived or recombinant therapies to manage rare and serious medical disorders. CSL Behring has awarded more than $600,000 in grants to patient organizations since the LEAD program was established in 2008.

The grant will be used to create the A-PLUS State Exchange Project, which will educate state advocates on the development of state insurance exchanges, including federally defined essential health benefits that establish the minimum requirements of exchanges. The project will also help state advocates educate patients about implementation of the exchanges and how they can participate to ensure that access to specialized care and treatments will be maintained in the plans offered through the state insurance exchanges.

Excerpted from CSL Behring news release December 2, 2011

Victor Grifols selected as Business Leader of the Year 2011 by the Spain – US Chamber of Commerce

Victor Grifols Roura, president and managing director of Grifols, has been selected as the “Business Leader of the Year 2011” by the Spain–U.S. Chamber of Commerce, the premier forum fostering commercial, economic and industrial relations between Spain and the United States. This award, given annually, recognizes the professional career of business leaders who stand out in their industries, as well as their contribution to the globalization of the economy. In the case of Victor Grifols, his leadership as sales manager of Grifols since 1979, and as president and managing director since 1987 has driven the transition of Grifols and allowed it to grow from a family company to the third largest producer of plasma protein therapies worldwide.

The award will be presented by Angeles Gonzalez Sinde, Minister of Cultural Affairs of the Government of Spain during the gala dinner that will take place on December 6th, 2011 at the Hotel Pierre in New York, and attendees will include notable political and business figures from both Spain and the United States.

Excerpted from Grifols news release December 7, 2011

2012 IDF Core Service Sponsors

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Biotest Pharmaceuticals
CSL Behring
Grifols
IgG America/ASD Healthcare/US Bioservices
Kedrion Biopharma
Octapharma
Sigma-Tau Pharmaceuticals
Jeffrey Williams, of Fredericksburg, Texas, ran the New York Marathon on November 6, along with over 45,000 other runners. One of the preeminent marathons in the United States, Jeff was ecstatic to be a part of it. Training to run 26.2 miles through the five boroughs of New York was certainly a challenge. But for Jeff, that wasn’t enough. He decided to raise money for IDF and promote awareness of primary immunodeficiency diseases in honor of his two sons, Edward (15) and Ethan (10), who both have CVID.

Jeff knows how fortunate his family is to have health insurance to help defray the cost of the boys’ infusions. Many other patients aren’t that lucky. As Jeff said, “we discovered the IDF later in our journey than I would have liked and have been amazed at the support, research, information and advocacy that this small group of dedicated folks have made available to individuals, caretakers, doctors, etc. involved with primary immune conditions. It is the hope of my family that we can meet our fundraising goal and in some small way, give back to this organization that has done so much for so many.”

Jeff raised over $3,300 for IDF. For more information on how you can raise money and promote awareness through an event like Jeff did, email Allison Mayberry, Director of Development, at amayberry@primaryimmune.org.

Congratulations Jeff, and thank you from IDF!

Jeffery pictured with sons Edward and Ethan

In Tune with Your Immune System

Battle of the Bands

This video for teens compares the human immune system to a rock band - it needs all the parts functioning to make great music! A battle of the bands occurs when the bad band--featuring bacteria, viruses and fungi--arrives and tries to prove who the best band is.

Early reviews are in and are overwhelmingly positive! Check out these comments from teens:

“It was a huge help! It helped me learn about my immune system”

“The graphics were cool and the characters were fine.”

“Now I have a better understanding of my immune system!”

“Cool and interesting!”

Created by IDF to help teens better understand their immune system and how it works, this video is great fun while being a valuable educational resource. To view “In Tune with Your Immune System--Battle of the Bands” go to IDF’s teen website, IDF Common Ground, www.idfcommonground.org, and click on the first video listed on the video player. You can also access it via IDF TV at www.primaryimmune.org/idf-tv.

WITH GRATITUDE
Honorary and Memorial Gifts – 10/15/11 to 1/31/12

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Luke Goodwin Altobelli
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Elizabeth Bald
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Edgar Cathcart
Lisa Codispoti
Patricia Cook
Joseph Dellorso
Erica Lynn Bodrock Drap
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Alex
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Edward Williams
Ethan Williams
Jeff Williams
Davis Young

These donations help IDF improve the diagnosis and treatment of patients with primary immunodeficiency diseases through advocacy, education and research. If you would like to make a donation, please go on our website, www.primaryimmune.org and click the “Please Donate Today” picture in the top right corner. You can also contact us in any of the following ways:

Phone: 800.296.4433 or 410.321.6647
E-mail: idf@primaryimmune.org
Mail: IDF, 40 W. Chesapeake Ave., Suite 308 Towson, MD 21204
IDF Retreats

For Persons Living with Primary Immunodeficiency Disease & Their Families

Hyatt Regency Milwaukee
Milwaukee, WI - June 22 - 24, 2012

Hilton Houston NASA Clear Lake
Houston, TX - September 7 - 9, 2012

For an updated IDF Calendar of events, visit www.primaryimmune.org/event-calendar.