2005 IMMUNE DEFICIENCY FOUNDATION NATIONAL CONFERENCE

Our Largest Gathering of Patients and Families Ever
Over 1,400 individuals arrived in Orlando, Florida to attend the 2005 Immune Deficiency Foundation (IDF) National Conference and celebrate the Foundation’s 25th Anniversary in June 2005. Dedicated to the memory of David Vetter, affectionately known as “David, the Bubble Boy” and all those affected by primary immune deficiency diseases, this conference marked the largest gathering of families affected by primary immune deficiency diseases ever in the world.

There were three days of learning, discussing and sharing. World-renowned immunologists shared their time and expertise with families. Attendees learned about scientific advancements in the diagnosis and treatment of primary immune deficiency diseases and gained skills needed to manage their health care. Carol Ann Demaret, David’s mother and IDF board member, gave an inspiring talk in the opening session. Dr. E. Richard Stehm provided an informative keynote address on the history of primary immune deficiency diseases. Through a legislative advocacy workshop and informative breakfast symposium, the important issues of intravenous immune globulin (IGIV) reimbursement, access to care and newborn screening to ensure earlier diagnosis for patients were explored. Families benefited from the opportunity to meet other families and enjoy the festivities of Walt Disney World, as well as talk with the faculty and our generous sponsors in the interactive exhibit hall.

Robert LeBien Receives IDF 25th Anniversary Achievement Award
At Friday’s banquet, the community joined founders Marcia and John Boyle in celebrating IDF’s Silver Anniversary and honoring important leaders in the Foundation. The IDF 25th Anniversary Achievement Award was presented to Robert LeBien for his commitment to IDF and the primary immune deficiency community for over twenty years. Bob joined the IDF Board of Trustees in 1984, served as Vice Chair of the board and continues to serve on the Executive Committee and chair the Scholarship Committee. He spearheaded the creation of IPOPI, the International Patient Organization for Primary Immunodeficiencies in 1992 and the IDF LeBien Visiting Professor Program is named in his honor.
Since my return in May, the Immune Deficiency Foundation (IDF) has experienced celebrations, as well as crises in access to intravenous immune globulin (IGIV) therapy, while providing all our regular programs and services. To say the least, the last six months have been an exciting time.

In June, we celebrated our 25th Anniversary at our Third National Conference at Disney World in Florida. Over 1400 people attended, making it the largest gathering of patients and families with primary immune deficiency diseases ever! It was rewarding to see people share common experiences and feel the sense of community of so many people who support the mission of IDF.

And then it was back to business. In the 25 years since I co-founded IDF, we have dealt with several threats to our community, including the IGIV shortage in the late 1990’s. However, I must admit that I find the present Medicare reimbursement issues truly frightening. Reductions in Medicare reimbursement have had a disastrous impact on many of our patients. The implications of these reductions are staggering, as many private insurers follow Medicare reimbursement rates. States, also feeling the impact of rising health care costs, are looking at ways to cut expenses. One state even proposed to exclude expensive benefits, like IGIV therapy, from their contract.

IDF has focused a great deal of time and effort on these issues. We have conducted physician and patient surveys that have provided the only data that documents the impact of Medicare changes on our patients. We have advocated on Capitol Hill and with the Centers for Medicare and Medicaid Services continuously since we learned of the rate changes a year ago. We have joined a group of other patient organizations, physicians and manufacturers and distributors of IGIV to increase our efforts.

But, what we need is you! The single most important role that IDF can play is to unleash the strength of our grassroots community. Members of Congress listen when patients, families and medical professionals in their states and districts contact them. I am asking everyone in our community to join our efforts.

We often need to quickly notify patients and supporters to contact key members of Congress or other officials about a pressing issue. We need your e-mail addresses so we have the ability to immediately alert you. We also ask you to sign up for IDF Action Alert, our online advocacy program. This program helps you to easily get your message directly to legislators and is critical to the success of our advocacy efforts.

Going forward, IDF will focus on building our grassroots network for patient advocacy, support, education and physician education. Our community needs to be heard; and together, we can ensure that individuals with primary immune deficiency diseases have access to quality health care and services.

It’s great to be back, but it is with a feeling of tremendous responsibility in knowing how essential IDF is to our community.

Marcia Boyle
Linda Keegan, the local area volunteer coordinator from Madison, Wisconsin, was honored with the IDF Volunteer of the Year award for her enthusiastic work with IDF and patient advocacy. In addition, Dr. Jerry Winkelstein was announced as the recipient of the Boyle Achievement Award for scientific achievement.

**Kick-Off Breakfast Symposium Explores Treatment Option**

Over 500 people attended the breakfast symposium where subcutaneous immune globulin therapy was discussed. Dr. Melvin Berger, a professor of medicine at Case Western Reserve University, described research he has done on administering immune globulin therapy under the skin, or subcutaneously. Fourteen-year-old Emily Ernst of Alexandria, Kentucky, and her mother Carol, an IDF volunteer peer contact, joined Dr. Berger to share their experiences with this route of administrating immune globulin therapy.

**The Art of Communication**

New to the conference this year was an art therapy program, designed to address the emotional challenges of living with a primary immune deficiency disease in a family setting. The program allowed children from ages 6 to 17 to express their feelings through a variety of art media. Many feelings were shared throughout the two-day series of exercises and each child contributed something honest, poignant and valuable to the group. Parents were encouraged to talk with their children about their experiences and continue to keep strong lines of communication open.

**Extravaganza at Epcot**

The conference ended with a boom! Everyone enjoyed an evening at Epcot, one of Disney’s premier parks. At the conclusion of the evening, a dessert reception offered front row, private viewing of “Illuminations Reflection of Earth,” a fantastic fireworks display. It was the perfect ending to a wonderfully successful national conference.
IDF FIGHTS MEDICARE REIMBURSEMENT REDUCTIONS

Hundreds of calls and letters from Medicare recipients and physicians have flooded the Immune Deficiency Foundation (IDF) since January when Medicare dramatically reduced reimbursement rates of intravenous immune globulin (IGIV) in physician offices, outpatient infusion suites and home care settings. Because of this reduction, many patients have not been able to receive their IGIV infusions in these settings. Many have been shifted to hospitals that are not equipped to handle their infusions, and often patients are not receiving their prescribed IGIV, but the brand the hospital has accessible. Even worse, some patients are on hospital waiting lists, denied access or treated with prophylactic antibiotics.

A further concern is that the difference in reimbursement that has favored hospitals over the past will no longer occur as of January 1, 2006. Hospitals will then be reimbursed under the same formula as physician offices and home care settings, creating even more problems with access to proper medical care.

IDF Takes Action

With this crisis, IDF has taken action at many levels on behalf of patients. IDF has intervened in several individual situations to ensure treatment for patients and has tirelessly lobbied on Capitol Hill for change. The Foundation mobilized grassroots volunteers to sign up for IDF Action Alert to directly contact legislators and recruit more Members of Congress to help in this effort. More than a thousand letters, stories and calls were made in five months through IDF Action Alert, resulting in more than fifty Members of Congress actively supporting this cause.

IDF initiated articles in The New York Times and a story for the Associated Press that described how the reduction in Medicare IGIV rates has disrupted patients’ lives. IDF even surveyed physicians and Medicare recipients to document the impact that reimbursement changes were having on our patient community.

“We thank the physicians and patients who participated in our surveys. There was no other information available on the impact of the change in patient care, so their involvement was vital. Our surveys produced the only quantifiable data that could be used to present to the Centers for Medicare and Medicaid Services and Members of Congress,” Marcia Boyle, President and Founder of IDF said. “We found that patients’ site of care was definitely shifted and that many individuals had experienced negative health outcomes.”

Recognizing the gravity of these issues, IDF was instrumental in forming a group of patient organizations, the American Academy of Allergy, Asthma and Immunology and manufacturers and distributors of IGIV to present a strong front to fight against the reduction in reimbursement.

In May, IDF testified at the Health and Human Services Advisory Committee on Blood Safety and Availability (ACBSA). The committee recommended that a public health emergency be declared to enable Centers for Medicare and Medicaid Services (CMS) to apply alternative mechanisms for determination of the reimbursement schedule of IGIV products.

Because of these efforts, approximately 30 Members of Congress requested that Mike Leavitt, Secretary of Health and Human Services, United States Department of Health and Human Services act upon these recommendations.

Some Improvement

In response to this ground swell, CMS announced it would establish a temporary add-on payment to cover the additional preadministration-related services required to locate and acquire adequate IGIV product and prepare for an infusion of IGIV during this current period of market instability. This is a new add-on billing code for both hospital outpatient settings and physician offices. The add-on code, G0332, has a payment rate of $75 for hospital outpatient settings and $69 for physician offices. This begins on January 1, 2006 and will be in effect for calendar year 2006 only.

In spite of the temporary compensation, the CMS preadministration add-on payment is not adequate to solve the reimbursement crisis facing patients with primary immune deficiency diseases. The add-on payment is not sufficient to cover all costs involved in administering IGIV therapy. CMS did not address the fundamental problem facing providers trying to service this community--reimbursement for IGIV under the current formula is just too low. Furthermore, reimbursement reductions have been proposed for Medicaid and several private insurance companies have matched Medicare’s reduced rates.

The Fight Continues

Much still needs to be done. IDF will continue to lobby Congress and CMS to establish a permanent and comprehensive solution to patient access to IGIV. Members of our community will be encouraged to send their stories and messages to Congress through IDF Action Alert. IDF will continue to intervene for individual patients to ensure proper treatment.

Reimbursement should never dictate where a patient receives their infusion. The reimbursement for IGIV under Medicare has negatively impacted patients’ lives and IDF will continue to advocate equal and adequate reimbursement of all brands of IGIV, in all sites of care.

Please visit our Web site at www.primaryimmune.org to join IDF Action Alert to directly contact Congress and CMS.
The Immune Deficiency Foundation (IDF) knows that its greatest strength comes from the dedicated people throughout the country who support our mission. Throughout the years, our supporters have accomplished incredible achievements on behalf of IDF, using their passion and drive to make a difference for people living with primary immune deficiency diseases. To sustain these efforts and give supporters the tools they need to be successful, IDF has formalized our grassroots efforts. With dedicated resources from Baxter Healthcare Corporation, Talecris Biotherapeutics and Patrick Schmidt, President FFF Enterprises, Inc. and NuFactor, the IDF Grassroots Advocacy Program was formed.

IDF Grassroots Advocacy Program will mobilize providers, advocates, patients, families and industry throughout the country to promote health care legislation. This is an opportunity for people personally affected by primary immune deficiency diseases to become directly involved in policymaking. Through this program, IDF and its volunteers will take the lead to ensure access to quality care, choice in intravenous immune globulin brands and infusion locations. We will address early detection of primary immune deficiency diseases, increased research funding, access to disability benefits and other issues relevant to our community.

So, get involved! Join the supporter list for IDF Action Alert, our online advocacy program that makes it easy for all individuals affected by primary immune deficiency diseases to impact legislation and regulations affecting them. Through IDF web site, www.primaryimmune.org, users connect with IDF Action Alert and can directly send their story and concerns to their elected officials. It is a simple and effective way for people to voice their issues and directly influence the political progress.

It is simple to register. With just three clicks, you can reach the registration site:

1. Go to our web site www.primaryimmune.org
2. Click IDF Action Alert on our Homepage
3. Click Join Our Supporter List and that will take you to the registration site

When you are registered, you will be able to:

- Receive updates and alerts on the primary immune deficiency diseases community issues
- Receive electronic action alerts
- Locate elected officials by zip code or name
- Use prewritten emails or letters and compose personal online messages
- E-mail, write or fax your letters and stories to Members of Congress, the President, and federal agencies
- Follow key legislation by accurately tracking current bills and cosponsor status
- Search for media outlets in your area and share your personal stories
- Receive tips on communication with elected officials and visiting Capitol Hill

In the last five months, over 1,000 messages were sent to Congress through IDF Action Alert. Register today to add your voice and help make a difference.

Special Thanks to Congressional Supporters for Helping Our Community during the IGIV Access to Care Crisis

Congressman Gary Ackerman (D-NY)
Congresswoman Tammy Baldwin (D-WI)
Congressman Xavier Becerra (D-CA)
Congressman Howard Berman (D-CA)
Congressman Michael Balkakis (R-FL)
Congressman Henry Bonilla (R-PA)
Congressman Sherrod Brown (D-OH)
Congressman Michael Burgess (R-TX)
Congressman Dave Camp (R-MI)
Congressman Nathan Deal (R-GA)
Congressman Phil English (R-PA)
Congressman Michael Ferguson (R-NY)
Congressman Bob Filner (D-CA)
Congressman Mark Foley (R-FL)
Congressman Virgil Goode, Jr. (R-VA)
Congresswoman Kay Granger (R-TX)
Congressman Gene Green (D-TX)
Congressman Raul Grijalva (D-AZ)
Congressman Aicee Hastings (R-FL)
Senator Orrin Hatch (R-UT)
Congressman J.D. Hayworth (R-AZ)
Congressman Brian Higgins (D-NY)
Congressman Maurice Hinchey (D-NY)
Congressman Mike Honda (D-CA)
Congressman Steve Israel (D-NY)
Congresswoman Sheila Jackson Lee (D-TX)
Congresswoman Nancy Johnson (R-CT)
Congressman Sam Johnson (R-TX)
Congressman Rick Larsen (D-WA)
Congresswoman Carolyn McCarthy (D-NY)
Congressman Jim McCrery (R-LA)
Congressman Gregory Meeks (D-NY)
Congressman Dennis Moore (D-KS)
Congressman James Oberstar (D-MN)
Congressman Butch Otter (R-ID)
Congressman Joseph Pitts (R-PA)
Congressman Todd Platts (R-PA)
Congressman Silvestre Reyes (D-TX)
Congressman Steven Rothman (D-NJ)
Congressman Bernie Sanders (I-VT)
Senator Rick Santorum (R-PA)
Congressman Adam Schiff (D-CA)
Congressman Pete Sessions (R-TX)
Congressman E. Clay Shaw, Jr. (R-FL)
Congressman Christopher Shays (R-CT)
Congressman John Shimkus (R-IL)
Congresswoman Hilda Solis (D-CA)
Congressman Cliff Stearns (R-FL)
Congressman Jim Walsh (R-NY)
Congressman Anthony Weiner (D-NY)
Congressman Jerry Weller (R-IL)
Congressman Robert Wexler (D-FL)
Congressman C.W. Bill Young (R-FL)
House Energy and Commerce Committee
Senate Finance Committee
Staff of the House Ways and Means Committee
KEY FACTS ABOUT AVIAN INFLUENZA

Avian influenza A (bird flu) is a contagious disease of animals caused by viruses that normally affect only birds. Although bird flu usually do not infect humans, several instances of human infection have been reported since 1997. Most cases of avian influenza in humans are thought to have resulted from direct contact with infected poultry or contaminated surfaces. Because of concerns about the potential for more widespread infections in humans, public health authorities closely monitor outbreaks of human illness associated with avian influenza. To date, human infections with avian influenza A since 1997 have not resulted in sustained human-to-human transmission. However, because influenza A viruses have the potential to change and gain the ability to spread easily between people, monitoring for human infection and person-to-person transmission is important.

Current Poultry Outbreak

The current outbreak of avian influenza A (H5N1) among poultry in Asia and Europe is an example of a bird flu outbreak that has caused human infections and deaths. Outbreaks of influenza H5N1 occurred among poultry in eight countries in Asia (Cambodia, China, Indonesia, Japan, Laos, South Korea, Thailand, and Vietnam) during late 2003 and early 2004. At that time, more than 100 million birds in the affected countries either died from the disease or were killed in order to try to control the outbreak. By March 2004, the outbreak was reported to be under control. Beginning in late June 2004, however, new outbreaks of influenza H5N1 among poultry were reported by several countries in Asia (Cambodia, China, Indonesia, Kazakhstan, Malaysia, Mongolia, Russia, Thailand, and Vietnam). It is believed that these outbreaks are ongoing. Most recently, influenza H5N1 has been reported among poultry in Turkey and Romania.

Human Infection

Human infections of influenza A (H5N1) have been reported in Cambodia, Indonesia, Thailand, and Vietnam. Most of these cases have occurred from contact with infected poultry or contaminated surfaces; however, it is thought that a few cases of human-to-human spread of H5N1 have occurred. So far, spread of H5N1 virus from person to person has been rare and has not continued beyond one person. There have been no human cases of H5N1 flu in the United States. It is possible that travelers returning from affected countries in Asia could be infected if they were exposed to the virus. Since February 2004, medical and public health personnel have been watching closely to find any such cases.

Is the U.S. blood supply safe from avian flu?

Currently, there is no indication that either the human blood supply or immune globulin intravenous (IGIV) in the United States are contaminated with the avian influenza viruses.

Is IGIV protective against avian flu?

IGIV should not be protective against avian flu, since humans have not been infected with avian bird flu except for a few people in Asia. It is possible that there could be some cross-reacting anti-influenza antibodies in IGIV that would be protective against avian flu, but this has not been demonstrated.

Should Primary Immune Deficient Patients take Special Precautions?

Precautionary measures for primary immune deficient patients include the following:

1. Limit travel to Asia and regions of the world that have had poultry outbreaks of avian flu.
2. Listen to news reports about the spread of avian flu to humans in the United States.

For More Information

The Centers for Disease Control and Prevention and the World Health Organization have the most up to date information on avian flu and potential outbreaks. Visit www.cdc.gov/flu/avian/ or www.who.int/csr/disease/avian_influenza for detailed information.

Visit our Web site for Influenza Update

Influenza, or “the flu”, can cause serious respiratory illnesses in normal people. Those with primary immune deficiency diseases may be at an increased risk for the flu and experience more serious complications. There are two types of influenza virus that commonly cause human disease, Type A and Type B. Each year these types undergo changes, which make individuals susceptible to infection even though they may have antibodies to other strains of influenza from prior infections or immunizations.

Additional information about the flu and treatment for individuals with primary immune deficiency diseases can be found in the article, Questions and Answers on Influenza, Killed Influenza Vaccine and FluMist® Influenza Vaccine. It is posted on our Web site at www.primaryimmune.org, or, if you prefer, just call the IDF office at 800.296.4433 to request a copy.
AROUND THE COUNTRY--VOLUNTEER PATIENT MEETINGS

Our Volunteer Support Network is a dedicated group of people who share their experiences and knowledge of living with primary immune deficiency diseases. They are instrumental in helping other patients and families in their local areas. This past year, some of our creative volunteers organized educational meetings for patients and their families.

In April, Gail and Syd Nelson organized a patient meeting in Baton Rouge, Louisiana. Dr. Prem Menon, from the Asthma, Allergy and Immunology Center in Baton Rouge discussed “Pros and Cons of Subcutaneous Infusions.”

During May, Susan Rhodes arranged for two speakers at an educational meeting in Denver. Dr. Isaac Melamed, from First Allergy and Asthma Center in Englewood spoke on “Interaction of the Immune System with other Organ Systems” and Barb Lindenbaum, RN discussed “Rapid Infusion of IGIV and Patient Experiences in an Infusion Suite.”

Also in May, Kathy Antilla held the “Minnesota Family Conference Day” which included youth program activities. Brad Wing, Physical/Health Disabilities Teacher, Intermediate School District 287 reviewed “What are my Child’s Educational Rights?” and Melaine Zeigler, an adult patient shared “Living a Full Life with a Primary Immune Deficiency.”

“Chill out with IDF” was a real family affair in Kent, Washington in August. There were games for younger children, lunch, and ice-skating for the whole family. Information on teen transitioning and subcutaneous immune globulin was discussed. Joanne Pease led this fun event.

Peggy Stadtmiller and Karen Wheat did double duty. In September, they organized an adult group meeting in Waterloo, Illinois and in October, in Fenton, Missouri, they arranged for Dr. Subramanian to present on primary immune deficiency diseases.

Linda Keegan spearheaded the “IDF Milwaukee Annual Conference.” It was held at the Milwaukee County Zoo in October and featured William J. Grossman, MD, PhD, of the Medical College of Wisconsin.

Fran Thompson organized an educational meeting at the Denver Aquarium in October. Dr. Jennifer Seda presented an overview of primary immune deficiency diseases and Dr. Charles Kirkpatrick and Kimberly Duff, RN participated on a panel on subcutaneous immune globulin.

Following the education sessions, everyone toured the aquarium.

In November, the Minnesota Fall Conference at the BioLife Plasma Services Center was planned by Kathy Antilla. Participants toured the Center and heard presentations on IGIV therapy from Patty Riley, RN and Dr. Ralph Shapiro. Teens also learned how to “Be Your Own Advocate,” while living with a primary immune deficiency.

Catharine Beal arranged an “Evening with the Expert” meeting in November. Dr. Melvin Berger led a question and answer session in Cleveland, Ohio.

The Immune Deficiency Foundation is extremely proud of our volunteers and their commitment to our mission. Thank you all for your dedication and remarkable work.

IDF local education meetings are generously sponsored by our Core Service Sponsors: Baxter Healthcare Corporation, Grifols, Nufactor, Octapharma, Talecris Biotherapeutics, US Bioservices, an IDF Preferred Provider, and ZLB Behring.

A Guide for School Personnel: Primary Immune Deficiency Diseases


The Immune Deficiency Foundation is delighted to announce the release of our new publication, A Guide for School Personnel: Primary Immune Deficiency Diseases. IDF developed this booklet to educate school personnel about primary immune deficiency diseases and the children who are affected by them. This booklet includes key medical points about primary immune deficiency diseases and associated special needs, legal rights of children with chronic disease and resource referrals for more information.

Perhaps most importantly, this guide should be used to facilitate effective communication between parents of children with primary immune deficiency diseases and school system personnel, including administrators, teachers and nurses. Meetings involving school personnel and parents are crucial to ensure the health and well-being of children in the school setting. This publication should serve as a basis for discussion at meetings and subsequent contacts with parents. Used in conjunction with information on a student’s specific diagnosis, personal medical history and current treatment, this guide will be a valuable reference for all school personnel throughout the school year.

The publication of the A Guide for School Personnel: Primary Immune Deficiency Diseases was made possible by a generous grant from the American Legion Child Welfare Foundation, Inc. IDF acknowledges the work of its staff and dedication of many volunteers who helped to make this publication possible.

Special appreciation is extended to Katherine Antilla, Rebecca Buckley, M.D., Diana Gill, Melissa Schweitzer and IDF Nursing Advisory Committee members for their efforts.

School personnel, parents and caregivers are encouraged to order a free copy of this informative booklet.

Please contact IDF at 800.296.4433 or e-mail idf@primaryimmune.org.
PATIENT ADVOCACY

“I’m feeling a bit desperate. I have been chronically ill for a number of years and my primary physician is willing to give me a referral, but doesn’t know to whom. Can you give me any leads to immunologists in my area who know something about this?”

“My home care will no longer infuse me because of reimbursement rates being so low. I am on Medicare and will have to drive 75 miles to the nearest hospital. My diagnosis is CVID. I have contacted my state representatives but what else can I do?”

“My daughter had two IGIV treatments and responded very well. This was covered by insurance at my last job. When I changed jobs, my new health insurance will not cover the cost of treatments. Do you have any suggestions on how to get the insurance company to cover the IGIV?”

“My sister was diagnosed with CIVD about 10 years ago. She is having a hard time and I was wondering if you have any contacts that could help provide support for her.”

“I am a pharmacist with a home care company. I am unable to obtain a specific IGIV product for patients. Do you have the manufacturer’s number, so I can call them directly?”

Responding to these questions is all in a day’s work for Serrie LaTorre Krash, the Patient Advocate Manager at the Immune Deficiency Foundation. She answers phone calls and e-mails from people searching for information regarding primary immune deficiency disease issues.

The questions deal with requests for physician location, literature, education, insurance and peer support. Two categories of calls, IGIV availability and IGIV Medicare reimbursement questions, which were rarely addressed in the recent past, have increased considerably in 2005. On average, there are about 12 calls a day; some take only a few minutes where others can take over an hour. Serrie works hard to answer them all.

“I wish I could fix everything for everyone who contacts me. Usually, I can answer the questions and refer people to resources, but of course, sometimes there are no answers. But, I really find my job rewarding,” Serrie said.

“I remember talking with one caller, who did not have a specific question, but just needed to talk with someone. She was exhausted and overwhelmed with all the doctor appointments and having trouble keeping organized. I asked her if she had a nurse case manager assigned to her from the insurance company. She was not familiar with this so I explained that case managers are advocates for coordinating the care between medical providers and the insurance company. This was exactly what she was looking for. This is what I find so rewarding.”

And sometimes Serrie checks her e-mail and reads:

“I followed the advice of the information you sent us and it worked. We have been fighting with our insurance company for a month, but today they approved the IVIG for my daughter’s treatments. Thanks for your help, without it, my daughter would not be getting the IGIV. People like you make this a better world.”

Not a bad way to start a Monday!

Serrie has extensive knowledge of health insurance, having worked nine years in the insurance business. She also has a Master in Health Administration and a Bachelor in Health Sciences. She can be contacted at 800.296.4433, extension 219 or sk@primaryimmune.org.

VICTORY IN MARYLAND

The Immune Deficiency Foundation teamed with the Hemophilia Foundation of Maryland, Advocacy for Chronic Conditions, Entitlements and Social Services Program (A.C.C.E.S.S.) and the Plasma Protein Therapeutics Association (PPTA) to advocate against excluding blood and blood products from the Maryland small group insurance market, which insures companies of two to fifty employees. The Maryland Insurance Commission originally proposed three options that would reduce premium costs and one of these options excluded blood and blood products from the standard insurance plan.

Along with representatives from the other organizations, Marcia Boyle, IDF President and Founder, addressed the Maryland Insurance Commission at their community meeting in November. Marcia testified about the necessity of blood and blood products for individuals with primary immune deficiency diseases. Likewise, the other team members expressed the needs of their groups. Because of these presentations, the commission decided against all of the proposed options. Uniting as a team with other organizations and being at the table proved to be a great win for our community in Maryland.
**INDUSTRY UPDATE**

**FDA Approves Baxter’s GAMMAGARD Liquid 10% for Patients with Primary Immunodeficiency Disorders.**

Baxter Healthcare Corporation announced that the U.S. Food and Drug Administration has approved GAMMAGARD Liquid 10% Solution for the treatment of primary immunodeficiency disorders associated with defects in humoral immunity. The ready-to-use, sterile preparation of GAMMAGARD Liquid 10% eliminates the need for reconstitution. The safety of GAMMAGARD Liquid 10% has been demonstrated in a wide spectrum of patients with primary immunodeficiency disorders. Baxter produces the therapy using a three-step viral reduction process, a unique combination used to help ensure viral safety. GAMMAGARD Liquid 10% is free of added sugar, sodium, and preservatives. Excerpted from Baxter News Release, May 2, 2005.

GAMMAGARD LIQUID does not have the same formulation as GAMMAGARD S/D: Baxter will continue to produce small amounts of GAMMAGARD S/D only for use with patients who have a high sensitivity to IgA. To learn more about transitioning from GAMMAGARD S/D to GAMMAGARD Liquid 10%, patients and health professionals can contact Baxter’s Medical Affairs at 1-866-424-6724.

**Labeling for Gamunex® now Includes Assurances of Removal of Pathogenic Prions During Manufacture**

Product labeling for Gamunex® (Immune Globulin Intravenous [Human], 10% Caprylate/Chromatography Purified) now contains data demonstrating the capacity of several unique steps in the manufacturing process to remove pathogenic prions, such as those associated with the development of variant Creutzfeldt-Jakob Disease (vCJD). This is the first such approval from the Food and Drug Administration (FDA) for a liquid IGIV (immune globulin [intravenous]) product. The new labeling provides quantitative information demonstrating a high margin of safety for Gamunex® against emerging pathogens, such as the abnormal pathogenic prion proteins associated with “Mad Cow” disease and vCJD in humans, creating additional confidence for patients and treaters.

The labeling states that the manufacture of Gamunex®, which incorporates the innovative Caprylate/Chromatography process for improved product purity and prolonged biological activity, provides reasonable assurance that potential infection risk is significantly reduced from pathogenic prions associated with Transmissible Spongiform Encephalopathies (TSEs), such as vCJD, in the unlikely event they are present in donated plasma. Excerpted from Talecris Biotherapeutics News Release, July 7, 2005

**ZLB Behring to Discontinue Production of Gammar-P I.V., Immune Globulin Intravenous (Human), at the end of 2005**

ZLB Behring will discontinue production of Gammar-P I.V., Immune Globulin Intravenous (Human), at the end of 2005. They determined that they can enhance IVIG production by offering a single lyophilized IVIG product, Carimune® NF. Carimune® NF is produced by a method that yields more IVIG per liter of plasma than their other IVIG, Gammar®-P I.V. This will allow them to increase availability of Carimune NF over time. Gammar-P I.V. will continue to be available through a select group of distributors and hospitals during a gradual phase-out through the first quarter of 2006. Excerpted from announcement by ZLB Behring on July 14, 2005

**IMPORTANT SAFETY INFORMATION**

**Interference With Blood Glucose Measurement Following Use of Parenteral Maltose/Parenteral Galactose/Oral Xylose-Containing Products**

FDA notified physicians, nurses, medical technologists, pharmacists and other healthcare professionals of the potential for life-threatening falsely elevated glucose readings in patients who have received parenteral products containing maltose or galactose, or oral xylose, and are subsequently tested using glucose dehydrogenase pyrroloquinolinequinone (GDH-PQQ) based glucose monitoring systems. There have been reports of the inappropriate administration of insulin and consequent life-threatening/fatal hypoglycemia in response to erroneous test results obtained from patients receiving parenteral products containing maltose. Cases of true hypoglycemia can go untreated if the hypoglycemic state is masked by false elevation of glucose readings. Excerpted from FDA Web site posting of Important Drug-Device Safety Alert 11/10/2005

Octagon 5% (Octapharma) and Gaminune N 5% (Talecris) contain maltose and are included in a preliminary listing of U.S. products that may cause glucose test interference that is provided on the Web site. For more information, visit: www.fda.gov/cber/safety/maltose110405.htm
The Immune Deficiency Foundation (IDF) is asking you to swap your usual work place attire for a pair of blue jeans! Blue Jeans for Healthy Genes is a special project where pulling on a pair of jeans raises money and awareness to fight primary immune deficiency diseases. Initially introduced in 2004, Blue Jeans for Healthy Genes has encouraged hundreds of men, women and children, all over the country to wear their blue jeans to save and improve the lives of people affected by these diseases.

Carol Ann Demaret, a member of IDF Board of Trustees, will serve as the Honorary Chair for IDF Blue Jeans for Healthy Genes 2006. Carol Ann’s son David was born with Severe Combined Immune Deficiency and became affectionately known to the world as “David, the Bubble Boy.” Her personal experience has defined much of her life as an advocate for newborn screening for primary immune deficiency diseases and a long time volunteer for IDF. She has ambitious goals for Blue Jeans for Healthy Genes and encourages everyone to become involved.

“I am always interested in supporting IDF and this project fills two important needs. First, funding is always needed to continue and expand the work of IDF through programs that improve the treatment and diagnosis of patients with primary immune deficiency diseases. And second, the opportunity to spread awareness of these diseases to the general public is enormous. What better way to reach people than through the workplace, schools or other places in their own communities!” Carol Ann stated. “I am really excited to be involved with a program with such potential.”

Blue Jeans for Healthy Genes is a special day, at the workplace, school or just about any community site, where people pay $10 for the chance to wear their favorite jeans. Aside from creating a fun atmosphere, the project also provides the ideal opportunity to educate those around you about primary immune deficiency diseases while raising funds for the IDF.

“It was a wonderful way to involve the kids and help them begin to understand what primary immune deficiency diseases are all about.” —Teri Wilkes

“Isn’t it time for you to get involved? Diana Gill, Program Manager for Patient Services at IDF is available to answer any questions about Blue Jeans for Healthy Genes. She has great ideas on personalizing this event to meet your own situation and will provide you with all the materials necessary to promote the event. Call Diana at 800.296.4433 ext. 302 or e-mail dg@primaryimmune.org to get started on your own successful launch of Blue Jeans for Healthy Jeans.”

Gail Nelson, a longtime volunteer of IDF, was awarded The Distinguished Service Award for 2005 at the annual meeting of the Louisiana Society of Asthma, Allergy and Immunology on June 11, 2005. Dr. Prem Menon presented the award to Gail for her many years of work with patients with primary immune deficiency diseases and their families, as well as her leadership in Louisiana.
This beautiful quilt made by the Friendship Quilters of Sun City, Arizona was raffled at the 2005 IDF National Conference and brought in over $3,000 in support for the Immune Deficiency Foundation. IDF would like to thank Dona McCready-Lewis and all the Friendship Quilters who gave their time and talent to increase awareness and education of primary immune deficiency diseases.

On June 12, 2005, Cheryl Hennen of Olivia, Minnesota coordinated the second “R.A.I.D.-Run Against Immune Deficiency”, a motorcycle run to raise awareness of primary immune deficiency diseases. Cheryl has two children affected by primary immune deficiency disease. Despite the rainy day, many people turned out to participate in the run and roast picnic that followed. This dedicated group raised over $400 for research and education programs for the Immune Deficiency Foundation.

In Morgantown, West Virginia, Mark and Lori Flood organized the “Valley Falls 10 Mile Run & 5K Walk” in honor of their daughter Amanda who has primary immune deficiency disease. Set up as part of a trail running series sponsored by the West Virginia Mountain Trail Runners, this first time event attracted 59 participants and raised $700 on October 8, 2005. Mark had previously run the Baltimore Marathon in 2003 to raise money for the IDF. Mark, Lori and Amanda plan to make this an annual event.

These donations help IDF to improve the diagnosis and treatment of patients with primary immune deficiency diseases through research, education and advocacy. If you would like to make a donation, please go on our Web site, www.primaryimmune.org, click the “How You Can Help” tab and use the secure online server. Or you can 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 Avenue  
Suite 308  
Towson, MD 21204

Combined Federated Campaign #9808
FAMILY RETREATS

The Immune Deficiency Foundation will host its Family Retreat Program in 2006. This marks the seventh year for the program.

The 2006 family retreats will lead families through “Best Care Boot Camp.” The weekend-long retreats will feature both scientific and life management workshops. Participants will have the opportunity to network with and learn from clinical immunologists, IDF staff, industry representatives and other families in an intimate setting. Fun and educational programming is also planned for children.

The dates and locations of the 2006 family retreats will be announced in the new year. Visit www.primaryimmune.org for the most up-to-date information.

Champions Circle of Support

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The Champions Circle consists of organizations committed to supporting the Immune Deficiency Foundation at the highest level. The Circle provides vital resources to fulfill the vision, mission and core services of the organization.

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