IDF Announces the Launch of New Revised Web site

IDF officially launched our newly revised Web site, introducing a fresh new look to www.primaryimmune.org, one of the main meeting places and information portals for the primary immunodeficiency disease community.

In addition to increased navigation and usability, the new Web site offers each visitor access to a wealth of information on primary immunodeficiency diseases, information on IDF’s mission, history, programs and events, and ways in which individuals can become involved in IDF activities and help spread awareness of primary immunodeficiency diseases.

The new Web site features easier access to an updated discussion forum, which now has an events calendar, a private messaging system, RSS feeds, anti-SPAM tools, member profiles, emoticons, and allows more individuals to participate and provide vital support for others. Also new to the Web site are specific sections for “Patients & Families” and “Healthcare Professionals” that will provide information that is tailored to their needs and interests.

Primaryimmune.org has become much more interactive as well. All IDF publications are now available to download in PDF form. And in addition to new “Contact Us” and “Ask IDF” forms, healthcare professionals can now request information on the Consulting Immunologist Program by instantly submitting an electronic form. Also new is the Internet-based continuing education course for nurses based on IDF’s new publication IDF Guide for Nurses on Immune Globulin Therapy for Primary Immunodeficiency Diseases, 2nd Edition.

IDF is excited about the changes that have already occurred as well as the future plans and possibilities for the new site. We encourage you to visit www.primaryimmune.org to see for yourself everything the new site has to offer!

The new, revised IDF Web site was made possible from a generous gift by Mike and Linda Guetz from Scottsdale, Arizona, through the Guetz Foundation in honor of Tara Guetz. Tara, daughter of Patti and Scott Guetz of Littleton, Colorado, was diagnosed with a primary immunodeficiency and Patti has been a dedicated volunteer and supporter of IDF for many years.

We also want to thank Talecris Biotherapeutics for their ongoing support of the IDF Web site.
IDF Capitol Hill Day 2008

IDF welcomed 50 volunteers from across the country to join us in Washington, DC on April 16-17, 2008. With great energy and determination, they walked the halls of Congress promoting greater understanding and awareness of the unique needs of patients with primary immunodeficiency diseases.

With a focus on the Medicare IVIG Access Act, a special emphasis was placed on contacting legislators who sit on Congressional committees with jurisdiction over Medicare legislation, which include the House Committees on Ways and Means and on Energy and Commerce, and the Senate Finance Committee. In that one day, IDF grassroots advocacy volunteers represented the primary immunodeficiency community and met with 93 legislative offices. Their personal stories and experiences from living with these diseases were invaluable in helping Members of Congress understand the critical importance of IVIG treatment. Each Senator or Representative was asked to join us in working to fix the current IVIG access and reimbursement issue by cosponsoring the Medicare IVIG Access Act and working to see it included in upcoming Medicare legislation.

Our Capitol Hill Day paved the way for the introduction of the Senate bill, S. 2990, The Medicare IVIG Access Act. Additionally, following the event we witnessed a distinct

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The Medicare IVIG Access Act
Reflecting on the Past, Looking to the Future

This year we saw our community vigorously unite over the common goal to fix the current injustice being forced upon patients with primary immunodeficiency diseases (PIDD) as a result of the inadequate Medicare reimbursement for IVIG and the currently empty home infusion benefit. There have been many great successes for us to reflect upon, and while we face new obstacles, we remain determined and optimistic as ever.

In May 2008, Senators John Kerry (D-MA), Lamar Alexander (R-TN) and Debbie Stabenow (D-MI) introduced S.2990, The Medicare IVIG Access Act. Similar to the House Bill 2914, S.2990 intended to improve reimbursement for IVIG and to provide coverage under the Part B home infusion benefit for related items and services for Medicare beneficiaries. The introduction of the Senate bill marked a moment of great success and we are extremely proud of the many IDF volunteers who were instrumental in conveying the importance of this legislation to their lawmakers.

Then in July 2008, the Medicare package passed in both the House and the Senate. It had been our goal to see S.2990 included in this package. However, the current political environment resulted in an extremely small package, and Senator Kerry and other supporters of the bill were unable to negotiate its inclusion.

We were dealt further bad news when the Centers for Medicare and Medicaid Services (CMS) proposed new regulations that would remove the preadministrative fee for the infusion of IVIG in physician offices and hospital out-patient departments. Additionally, reimbursement for infusions in hospital out-patient departments would also be reduced to ASP +4% under the new rules.

In response to this unfortunate proposal by CMS, IDF has initiated a campaign with the many supporting groups of the Medicare IVIG Access Act to appeal to CMS to reconsider their decision. We have already begun discussions with the 60 Senators and Representatives who have signed onto S.2990 and H.R. 2914 to ask for their support in explaining the further complications that Medicare beneficiaries may face if these changes are implemented.

We are fortunate to have a strong base of Congressional support, made possible through the tremendous efforts of our patients, families and volunteers throughout the country. It is with this support and great momentum that we will launch into the next Congressional year with our hopes high.

increase in Congressional support. Twenty-one additional Members of Congress signed on to cosponsor the House and Senate bills, many of which are directly attributed to meetings with IDF volunteers. We are extremely appreciative of all the time and effort our volunteers have put into supporting these vital legislative efforts, both in Washington, at home, and by signing onto the IDF Action Alert.

Reimbursement should never dictate if a patient receives lifesaving therapy, where a patient receives lifesaving therapy and when a patient receives lifesaving therapy- and no one can express that better than all of you. IDF is so proud of our advocacy volunteers’ commitment and dedication to the future of all patients living with primary immunodeficiency diseases.

We would like to offer special thanks to the sponsors of IDF Capitol Hill Day 2008, Baxter Healthcare, CSL Behring, Grifols, and Talecris Biotherapeutics for their generous support.
In a perfect world, all healthcare providers would be patient, understanding and have all the time in the world to answer all your questions and give details that you can understand. In that perfect world, every patient would be patient, understanding and know how to explain things so that every healthcare provider could comprehend. Unfortunately, we all have to deal with reality! Hopefully the following ideas will help guide you to get the most out of your healthcare visit.

The Team

Your primary care provider is the anchor on your team. Choose a doctor or nurse practitioner experienced with patients working with a multi-specialty team and willing to act as a filter for the information provided by your specialty providers. When looking for a specialist, ask for referrals from your primary care clinic, friends, family, and other health professionals. Be aware that frequently, primary care clinics are forced to refer within their own systems even if a good choice for a specialist is located elsewhere.

Don’t forget about other healthcare providers that can get things done for you. Nurses can be your best friends in communication; they are trained to facilitate communication between patients and providers. Pharmacists, physical and occupational therapists, social workers and mental health counselors are also important team members who may be involved intermittently or in some cases, daily. Get to know them and ask for the best communication options for their clinics.

Both you and your healthcare team have responsibilities to make communication effective. Your team members need to be respectful, truthful, responsive, accurate and good listeners. The flip side is that your responsibilities are identical.

Communication Dos

Write it down! List your questions, symptoms, and take notes during your visit. This will help you organize your thoughts. Prioritize your questions and concerns ahead of time and don’t be afraid to ask your provider how many questions there is time to address. If you have ten items on your list, you may not get through all of them in one visit.

Make your questions specific, such as “What are the side effects of this new medication?” Rather than saying, “What is wrong with me?” try to be explicit, “Explain to me which part of my immune system is responsible for my symptoms.” Repeat your understanding of the answer back to your provider, “I hear you saying that preventive antibiotics are safe for my child.”

Using statements beginning with “I” will work better with your providers than “You” statements. For example, “I don’t understand...” works better than “You are not being clear.” Try, “I didn’t understand what you just said. Would you explain it in a different way?” At the end of your visit take a minute to repeat back some things that you heard, “I understand that we are to get vaccinations from our primary clinic before we come back in six months...is that correct?”

Ask for information in writing. Many specialists keep a library of patient information just for your diagnosis.

Remember, you deserve to have your questions answered. Knowing you can ask questions builds trust with your healthcare team and will help create the best treatment plan for you.

Communication Don’ts

Do not be late for your appointments. You may have spent countless hours in waiting rooms for behind schedule physicians, but you may be turned away if you are late. Most providers work hard to stay on schedule; unfortunately emergencies may cause delays, but in most cases your patience will be rewarded.

Do not dwell on past experiences. We understand that patients with chronic health concerns may have some unsatisfactory interactions with doctors and nurses. Don’t come into a new relationship with that old baggage. Start the relationship on a positive note.
Do not be afraid to ask for a second opinion. Any provider who cares for individuals with chronic health concerns would welcome other opinions, and your provider may even be able to suggest an appropriate physician for that opinion.

Do not bring up huge issues at the end of the visit. Doctors dread the, “By the way doc...” as they walk out the door. This statement is usually followed by some horrific symptom such as chest pain and causes every provider to bristle. The only exception to this is, “By the way doc, I left some chocolate chip cookies for you at the desk.”

How Doctors Communicate

Communicating face-to-face is always the best option. This is the only acceptable forum to bring up NEW issues. When you are sitting in front of your doctors you will have their undivided attention. Try to make your expectations clear when scheduling your appointment so that the appropriate amount of time can be assigned to your visit.

Healthcare providers do much of their communicating in writing. Ask your provider to send a copy of his or her impression to you and your list of providers, especially your primary care provider. Keep in mind that the written communications from your specialists are usually not written in lay terms.

Communicating by phone is certainly more convenient for the patient, but for the provider, the phone can be a liability. Phone conversations are only acceptable once a relationship is established. Make sure that the “rules” of office triage are understood. What kinds of issues can you call about? How long will it be before you will get a call back? What issues are appropriate to call about? What are you to do in case of an emergency?

Final Thoughts

Since everyone’s communication style is different, you need to find an approach that is comfortable for you and makes the most of the time you have with your healthcare team. Try out some of these suggestions and see if your next meeting is more effective and you feel more confident and prepared to manage your symptoms. Good communication can help you participate in making informed decisions about your medical care and lead to better health outcomes.

Kristin Epland is a nurse at the Midwest Immunology Clinic in Plymouth, Minnesota. She serves as an active member of the IDF Nurse Advisory Committee.

Sometimes you must wait for weeks or even months for the opportunity to communicate with a healthcare provider. Don’t miss out on this chance to make your case with a specialist because you are unprepared. Here are a few tips on what to bring to your first visit with a new healthcare provider:

- Copies of past medical records that you can give to your provider—It takes time to copy the records at the visit
- Names and address of consulting and primary doctors
- Accurate list of current medications
- A second set of ears—One family member or friend with whom you are comfortable

After your initial visit, it is important to keep the lines of communication open with your team. Keeping routine follow-up visits is important. In fact, not routinely meeting with your team face-to-face means they are not thinking about you. Ask how often you should be seen and stick with the schedule. On follow-up visits, be sure to bring:

- Illness journal or calendar
- Updated medication list
- Copies of medical tests done in the interim
- Lab results
- X-ray films
- Copies of consults from other doctors
- Correct insurance information
How Do You Pass the Time?

Immunoglobulin treatments, by either intravenous (IVIG) or subcutaneous (SCIG) delivery, is a time consuming process. So, how do patients with primary immunodeficiency diseases pass the time receiving their treatments? We asked that question to patients and parents across the country and learned that the primary immunodeficient community is filled with innovative, positive multi-taskers who definitely see the glass half full!

And it is not just children who get special treatment or get to create happy memories. Joy Milling from Mississippi remembers receiving infusions at the local hospital where she worked years ago. She would sign in as an out-patient at 4:00 AM and go back to work while her meds were being prepared. When her work day was over, she would spend the next 8 hours getting her infusion. She gratefully recalls, “My friends from work would come by and my precious Mom felt she should come and sit with her ‘baby.’ This did allow for many hours of quality time together and for that I will always be grateful.”

Some people use their treatment time constructively. Industrious Kira Grischow, from Ohio, reported that she uses her mobile IV pump and pole during home infusion to do laundry, make dinner, help with homework, and all the “normal” things that a day entails. “Rather than viewing it as an inconvenience—I take advantage of the 3 hours and enjoy the downtime. It’s all in how you look at it. I have this disease, but I also have the blessing of available treatment. I design and make sterling/gemstone jewelry, so it’s the perfect time to sit and create. Not a bad time to catch up on a good book either!”

Susan Branch works her way down her to-do list: Her list of accomplishments includes:

1. Writing my Christmas cards— I finish at the same time my infusion is done.
2. Rewriting my address book— another one of those things that you can never get done or have time to do.
3. Setting up appointments on my cell phone.

However, she admits that not all infusions times are that productive and she often takes a little nap. And she is not alone.

Elizabeth Pennington from Oklahoma writes that her daughter “Princess” Jadon “gets the luxury of doing SCIG at home while making the most of her time with toys, games and movies. Jadon gets the royal treatment with her whole family catering to her every need. It has been such a blessing to have her at home and she gets to have the support of her three younger brothers...well entertainment might be more appropriate! Jadon also picks the dinner for that evening. She is a deserving princess here at home, we are proud of her courage!”

A room at the hospital filled with toys, movies, crayons, coloring books, art supplies and fun activities enables six year old Nicholas Muccioli to look forward to his IVIG treatments in Grosse Pointe, Michigan. Nicholas's mom, Denice, gets to dedicate some one-on-one time with her son. Even as Nicholas receives treatment, they shop in the gift shop, wrap up in a nice warm blanket and watch television together. They credit the wonderful nurses for their enjoyable experience.

Elizabeth Pennington helps her daughter Jadon with her SCIG.
Janet Darby in Florida starts her infusion in the evening, watches some TV, then goes to bed and sleeps till it is done. Gail Nelson from Louisiana thought her story wasn’t very newsworthy, “I do nothing but sit on the couch, visit with my nurse, and read or watch TV or nap.” Leslie Mink joins the group, “I don’t think you want my story—I sleep.”

However, nothing could be farther from the truth! In fact, naps can be one of the most luxurious gifts you can give yourself. No need to feel guilty—just enjoy!

Enjoyment is key for many. In Massachusetts Stefani Bush reported about infusion parties for groups of 5 or 6 kids. They begin their infusions together, play games, eat good food and enjoy cake. She believes that it helps them feel that they have some power and control and can have some normalcy within a group of their peers.

Almost everyone used some form of new technology during their treatments. When Fran Starr-Schnee from Florida went to an infusion center, she had her business calls forwarded to her cell phone and always took her laptop, for researching, writing friends and checking e-mail. Her sons bought Fran an iPod to listen to relaxing songs which she loves.

Gary Trump from Washington State wrote that his two sons Darren and Chris who have CVID do different things, but their favorite activity is playing video games. The hospital provides a gaming system and infusion typically takes less than 2 hours, so not much diversion is needed. TV and movies are also available.

And speaking of movies, when David Toye, a teen from Texas received IVIG he brought his portable DVD player to watch movies or read a book. Now he gets SCIG and enjoys playing on his computer or writing a story.

In New York, Beverly Lawton’s seven year-old daughter passes time watching movies and playing Webkinz on the Internet while doing SCIG. But in the warmer weather she is a little less high tech mimicking her mom by taking a book, stretching out on the deck and reading in the sun. Even neighbors stop by to chat.

Sue Mathis from Ohio uses some of her infusion time for self-reflection and shared some of her thoughts, “I get my IVIG once a week at a hospital infusion suite and I am there for 6 to 7 hours. Other patients are there getting chemotherapy and other types of IV medications and I usually talk to a few of them. Talking to people going through chemotherapy and seeing how sick they are makes me very thankful that all I have is an immune deficiency.”

And Terry Halper, a longtime volunteer in Pennsylvania, never lets a chance go by to spread awareness and educate others. He wrote, “When I get my monthly infusion, I educate the nurse on primary immunodeficiencies. Often times the nurse will have at least one other patient with PIDD so I offer IDF literature to the nurse to keep and/or share with other patients. I also include permission for the healthcare provider to share my contact info with other patients.”

We at IDF love to hear about anyone spreading the word about primary immunodeficiencies and IDF. Thank you to all of you amazing people!
Free IDF Internet-Based Continuing Education

Nurses Can Earn Free CE Credit at Their Convenience

The Immune Deficiency Foundation is proud to offer the Continuing Education course based on its publication *IDF Guide for Nurses on Immune Globulin Therapy for Primary Immunodeficiency Diseases*. This free Internet-based course was developed by the IDF Nurse Advisory Committee, a group established by IDF in 1999 to improve the quality of healthcare and education provided by nurses for patients with primary immunodeficiency diseases.

This CE Course is targeted for certified registered nurse infusionists (CRNI), registered nurses (RN), and licensed practical nurses (LPN) to enhance their professional skills by familiarizing them with immunoglobulin replacement therapy, including:

- clinical uses
- product characteristics
- infusion management
- complications of therapy

Accreditation is provided through the Health Communication Research Institute, Inc., a CMA-accredited provider. Participants will receive 1.0 contact hours for their participation in this session. Please check with your individual state for specific requirements for continuing education credits.

To access the CE Course on Immune Globulin Therapy for Primary Immunodeficiency Diseases, go to the IDF Web site, www.primaryimmune.org.

About the IDF Nurse Advisory Committee

The Nurse Advisory Committee is available as a resource for nurses administering immune globulin therapy or treating patients with primary immunodeficiency diseases. The members can be reached by contacting IDF and staff will assist in contacting a member of the committee. Please contact IDF at 1-800-296-4433 or idf@primaryimmune.org.

The activities of the Nurse Advisory Committee are made possible by an unrestricted educational grant by CSL Behring.

SCID Initiative

The Immune Deficiency Foundation is proud to announce the creation of a new Severe Combined Immune Deficiency (SCID) Initiative. Driven by requests from our SCID community, a new dedicated fund has been created for the purpose of supporting SCID specific programs including: education, awareness, diagnosis, newborn screening, and the search for a cure. The creation of the SCID Initiative is a new step for IDF, as this is the first disease specific initiative to be proposed by the organization. As another first, IDF has developed an oversight committee for the SCID Initiative fund which is comprised of community members with specialized interest and knowledge specific to SCID. It is hoped that the creation of the SCID Initiative will encourage IDF's members and supporters with an interest in seeing the development of new SCID programs, to step up by contributing specifically to the SCID Initiative. The program goals that the SCID Initiative desires to accomplish cannot be met without community support and resources. The first program that the SCID Initiative supported was the SCID Conference 2008. More specifically, the SCID Initiative provided additional scholarships to assist families who might not otherwise have been able to attend.

The opening contribution to the new SCID Initiative has been made by Molly Rennels and her fiancé Nick Lazzara as part of their wedding commitment to one another. The donation is being made in memory of two members of Molly’s family, Raleigh Houck and Colin Marquard, both of whom lost their battle with SCID.

Anyone wishing to make a contribution to the SCID Initiative should direct their contribution to: Immune Deficiency Foundation - SCID Initiative 40 W. Chesapeake Avenue Suite 308 Towson, MD 21204

All contributions will be fully tax deductible, as are all donations made to Immune Deficiency Foundation.
IDF Volunteer Leadership Conference 2008

A Letter from a Volunteer

Baxter Healthcare Corporation generously sponsored the IDF Volunteer Leadership Conference in Chicago, in May, and it was truly an inspirational time! For the first time I was thankful to have CVID. You may ask “WHY?” but I was able to be part of an incredible group of people. I, personally, had the pleasure of meeting Marcia Boyle, the President and Founder of IDF, Kathy Antilla, the tireless person who supports all the Peer Supporters, Diana Gill, who put together this informative convention, Christine Belser who works to get out the information we all need, and the rest of the staff. Along with knowing who keeps this organization flowing so smoothly, I met parents whose children have been on IVIG almost since birth and other patients, the same as me.

There is nothing quite as supportive as PEER Support itself!

Once again, we were reminded that we are the fortunate ones because we have a diagnosis. This became one of the themes of the conference— “Attitude of Gratitude.” We are the ones who need to be grateful there was an informed doctor who not only listened to us, but ordered the correct tests so we could improve our lives. We need to continue to inform and educate our doctors; this is one of our obligations.

I encourage everyone who reads this newsletter to honor yourself by becoming part of IDF and networking as a gift to yourself. The rewards are beyond words.

Bonnie Ritt — IDF Volunteer from Florida

Samantha (Sami) Jankins, Miss Wisconsin ANTSO (America’s National Teenage Scholarship Organization), new IDF Volunteer and CVID patient was on hand to entertain the volunteers in the Empire Room at the Palmer House Hilton Hotel in Chicago. Sami is in her senior year of college at the University of Wisconsin, Milwaukee and is studying acting, directing, design and costuming.

Pat and Ed Ganley, new IDF volunteers from Florida, enjoy meeting other volunteers and learning about IDF.

Matt and Jill Heaps, volunteers from Utah benefit from a weekend of sharing experiences and meeting new volunteers.

Volunteers Jan Christensen, California, Bonnie Doak, California, and Gail and Syd Nelson, Louisiana are presented with the “IDF Dedicated Volunteer” awards. All four recipients have devoted their time and energy to IDF for many years and have served as volunteers in many capacities.

Barb Ballard, Virginia, and Heather Smith, Florida, long time IDF volunteers, ride the bus for the night’s entertainment at the Second City Comedy Club. Barb is also a member of the IDF Board of Trustees.
Volunteer Fundraising

Lisa Finethy celebrated her 40th birthday in style, by throwing a “FunRaiser” to benefit IDF. Shown here with husband Billy (right) and the talented auctioneer who helped Lisa raise over $12,000 for IDF. Thanks to Lisa and all her generous friends in Alton Bay, New Hampshire!

With Gratitude

Gifts In Honor Of
Courtney Abrams
Jennifer Daniels Andreas
Isaac Antilla
Kathy Antilla
Allene Atwood
Kathi Beiswenger
Laura Bekier
John Boyle
Adam Brock
Nate Burdick
Kristin Buyer
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Memorial Hospital Outpatient Infusion Center
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Fran Starr-Schnee
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Jane Cooper
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Tish Clark Robinson
Jaqueline Routman
Rachel Roy
Vincent Sherburne
Betty H. Sherrard
Judith R. Stall
Patricia Warren
Kimberly Williams

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. 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 Avenue, Suite 308, Towson, MD 21204
Combined Federated Campaign #9808

Volunteer Yvette Shorten, organized a Blue Jeans for Healthy Genes Day at the Law Enforcement Management Institute of Texas, and the criminal Justice Center at Sam Houston State University - Huntsville, Texas as pictured here.

(L-R) Yvette Shorten, Marthalene Dosher, Amanda Burris, Teri Neiderhiser, Janet Mullings, Ann Broussard, Tammy Winkler, Carolyn Watson, Debra McCall, (not pictured) Gaylene Armstrong, Cutty Gilbert, AK Khan, Tess Johnson, Harriet Brewster, Howard Henderson, Diane Clark, Cecil Marquart, Sarah Kerrigan, Jamie Tillerson, Charlotte Harding

Volunteer Fundraising

CSL Behring Blue Jeans for Healthy Genes

(L-R, Front to Back): Rick Bartels, Assoc Director, Immunology; Laurie Harding, Product Mgr; Vivaglobin; Beverly Leymon, Mgr, Market Research CC&I; Bob Lefebvre, VP and Gen Mgr US Commercial Operations; Courtney Greaves, Sr Product Mgr, Berinert; Marian Hayes, Sr Product Mgr, Ig Products; Ronan Gannon, VP, Marketing.

The CSL Behring campaign was a huge success! ZLB BioPlasma, Boca Raton, FL and CSL Behring Kankakee, IL joined in the efforts and the three locations collected a total of $3,045.

Julie Lombardo completed her first triathlon on June 14, 2008. On a whim, she decided to use the triathlon as a way to raise money for IDF to honor her husband Jon. Shown here (left) with fellow triathletes Bob Dunn and Seana Gaherin, and her biggest fan, daughter Jordyn, Julie raised over $1,500 for IDF. Like their IDF shirts? You can buy them at www.cafepress.com/idf_gifts!
L-Proline Stabilized Immune Globulin Intravenous (Human) 10% Liquid, Privigen™, Demonstrates Good Tolerability at High Infusion Rates

CSL Behring announced data from a study that demonstrates its new liquid immune globulin intravenous (human) 10% product (Privigen™), is well-tolerated in patients with Primary Immune Deficiencies (PI); a group of predominantly genetic disorders that cause a malfunction in part or all of the immune system. New data from an additional study also showed that Privigen is well-tolerated when administered at high infusion rates. Both studies were presented at the American Academy of Asthma & Immunology (AAAAI) Annual Meeting in Philadelphia, U.S.

The extension study aimed to assess the tolerability and safety of Privigen when administered at infusion rates higher than those of the pivotal study (12 mg/kg/min, as opposed to 8 mg/kg/min). Results showed that Privigen is well-tolerated at high infusion rates with no temporally associated adverse events requiring an infusion rate reduction or termination during the study. This higher infusion rate may translate into less time spent in the hospitals for patients.

Excerpted from CSL Behring News Release March 17, 2008.

Baxter Presents Latest Clinical Trial Results of GAMMAGARD LIQUID Administered Subcutaneously

Baxter International Inc. announced the preliminary results of a Phase I/II clinical trial, in which subcutaneous infusion (under the skin) of GAMMAGARD LIQUID [Immune Globulin Intravenous (Human)] (IGIV) with Enhance™ Technology enabled administration of a full monthly dose via a single site to patients with primary immunodeficiency (PID).

GAMMAGARD LIQUID is approved for intravenous administration, which due to large infusion volumes of the therapy needing to be delivered, can take several hours once a month at a doctor’s office or hospital. By contrast, subcutaneous administration of IGIV has been limited by the inability of the tissue to absorb large volumes of injected drugs, creating the need to administer the therapy in smaller, weekly doses and through multiple injection sites. Subcutaneous administration of GAMMAGARD LIQUID with Enhance Technology via a single site could allow patients to administer a sufficient dose of IGIV once monthly at home.


Study Shows Privigen™ 10% Liquid Immunoglobulin Preparation for Intravenous Use, Is an Effective Replacement Therapy in Patients with Primary Immune Deficiencies

CSL Behring presented data on the pharmacokinetic properties of its new immune globulin intravenous (human) 10% product, Privigen™. Researchers found that Privigen leads to immunoglobulin G (IgG) pharmacokinetic characteristics and specific antibody levels equivalent to those described for other intravenous immunoglobulin (IVIg) preparations. The study was presented at the American Academy of Asthma & Immunology (AAAAI) Annual Meeting in Philadelphia, U.S.

Excerpted from CSL Behring News Release March 17, 2008.

Undiagnosed Primary Immunodeficiency Disorders are Associated with Substantial Healthcare Cost and Resource Use

Baxter International Inc. presented the results from a study that showed undiagnosed Primary Immunodeficiency Disorders (PID) are associated with a substantial cost and resource use burden within the health care system. The average medical costs attributed to undiagnosed PID patients totaled $42,039 per year and were due to use of outpatient, inpatient, emergency room and pharmaceutical resources.

The study found that the average medical cost per patient was $42,039 per year; with outpatient ($22,558) and inpatient ($12,983) costs acting as the main contributors. The study subjects visited a physician an average of 27.2 times per year and were admitted to the hospital an average of 0.7 times per year, with five days being the average inpatient length of stay.


Octapharma’s 25th Anniversary Gala

Octapharma, the largest privately held plasma fractionation company in the world and manufacturers of Octagam®, is celebrating its 25th anniversary in 2008. To celebrate its birthday, Octapharma invited selected friends, customers and associates to a festivity weekend in Heidelberg, Germany, where the chairman of the company, Mr. Wolfgang Marguerre resides. The first highlight of the weekend was the Opera of Wolfgang Amadeus Mozart “The Marriage of Figaro.” This was followed by a three hour scientific symposium in which well known international speakers presented the milestones in the development of the Octapharma products and treatment areas. Presenters included: Prof. L. Aledort, USA; Prof. E. Berntorp, Sweden; Prof. H. Chapel, UK; Prof. R. Dodel, GE; Prof. S. Meuer, GE; Prof. B. Solheim, NO; and Prof. H. Riess, GE. A Gala Dinner and fireworks ended a weekend of celebration. Marcia Boyle, the president of IDF, was honored to attend this exciting celebration.

Wolfgang Marguerre (3rd from right), Chairman of Octapharma Group, and Family.
IDF Core Service Program and Sponsors

Because primary immunodeficiency diseases are chronic conditions, continuity in IDF programs is one of the most important aspects of the services provided by our Foundation. Individuals living with primary immunodeficiency diseases - as well as their families - need to know that these services will be available throughout their lives. They need to know they can consistently count on IDF.

To ensure this, IDF created the “Core Service Program” in the spring of 2000. This year, our 2008 IDF Core Service Sponsors are:

- Baxter Healthcare Corporation
- CSL Behring
- Grifols
- IgG America / ASD Healthcare
- Octapharma
- Talecris Biotherapeutics

Core Services include direct services such as patient advocacy, peer support, local patient meetings and volunteer activities. Medical and scientific programs like our Consulting Immunologist Program and the LeBien Visiting Professor Program, as well as medical meetings and exhibits are included. Public Policy efforts such as grassroots advocacy, IVIG reimbursement and access to quality healthcare are also part of this vital program.

IDF relies on the generosity of these dedicated sponsors that support IDF at the highest level. They make an enormous difference in the Foundation’s ability to plan and provide long-term programs on behalf of people with primary immunodeficiency diseases. IDF greatly appreciates these sponsors and their commitment to our mission.