Wha tmight surprise you is the reasoning behind that desire.

“The National Conference has been life-changing for so many,” Marcia Boyle tells me, leaving the highlighting of its noted medical and education programs and entertaining activities to marketing. “When you attend (the conference) you can look around and see hundreds of our patients and families that feel less isolated – less alone – as a result of our conference.”

If you know Marcia, you know that her no-nonsense answer reinforces her serious approach to standing beside (and fighting on behalf of) the primary immunodeficiency community.

If you have yet to make her acquaintance, then perhaps a quick introduction is in order.

Marcia Boyle and her husband, John, didn’t set out to form a foundation; it arose from a distressing scenario in which no parent wishes to find his or herself: as the result of having a very sick child.

Prior to the trying times that lie ahead, Marcia graduated from college, and later obtained a Master’s Degree in Library Science, and, after spending numerous years in New York and New England (she was born in Massachusetts) found herself living in Columbia, Maryland.

That connection to the library sciences would prove monumental to Marcia personally, and instrumental in the founding of IDF.

“Our son was very ill,” Marcia explains. “The first year-and-a-half was pretty rough.” Once her son, also named John, was diagnosed with a primary immunodeficiency disease and received the necessary immunoglobulin replacement therapy, he was well on his way to recovery and an increased quality of life.

Marcia admits she was fortunate; her son’s diagnosis came quickly – something of great importance for which the IDF president has tirelessly advocated for the past 30 years.

Determined to research and absorb as much information as she could about her son’s primary immunodeficiency, Marcia took advantage of her library connection and digested the limited publications pertaining to the disease.

Still, with her focus fixed – naturally - on the wellbeing of her son and her family, Marcia’s journey through the then-practically unknown realm of primary immunodeficiency revealed a glaring absence of not only information and continued on page 3
Join us as IDF travels westward for the first time for the 2011 National Conference!

By popular request of many in the primary immunodeficiency community, IDF will be in Phoenix June 23-25 to Celebrate 30 Years of Advocacy, Education and Research at the IDF 2011 National Conference! This conference will continue the traditions of our previous conferences, but this time with a little western flair in the beautiful setting of the JW Marriott Desert Ridge Resort and Spa.

To see the full IDF 2011 National Conference registration brochure, which details all the sessions and events, please visit our website, www.primaryimmune.org or call 800.296.4433 to have one sent to you.

There is nothing like an IDF National Conference—and this time it is more grand than the Canyon, so if you haven’t registered yet, what are you waiting for?

Easy Online Registration

Now available on our website: www.primaryimmune.org

And even better, if you register online for all conference sessions, social events and youth programs, you will be entered to win a $500 gift card!

Need a Little Assistance?

IDF National Conference Scholarships

A limited number of partial scholarships are available based on financial need and are provided on a first come, first served basis. The partial scholarship covers hotel costs only (June 23, 24 and 25); registration and travel costs are not included. Because of the limited number of scholarships available, preference will be given to first-time conference attendees.

To apply, please complete the “Scholarship Application” section on the online registration form. You will be asked to upload a letter that includes information describing your diagnosis, your financial need and the benefit you hope to derive from attending the conference. For more information, contact the IDF National Conference Office at 414.918.3022 or conference@primaryimmune.org.

Many Thanks to Our National Conference Sponsors

Legacy Sponsors

Baxter Healthcare
CSL Behring
Talecris Biotherapeutics

Silver Sponsors

Grifols
IgG America/ASD Healthcare/
US Bioservices

Talecris Biotherapeutics
materials for patients and families, but also a lack of organizations working on behalf of those diagnosed with the disease.

“There was absolutely nothing out there – not a single organization at the time that was advocating or lobbying on behalf of immunodeficient patients.” Marcia says. “And there was nothing out there to help the families; no one out there to even talk to them.”

Enter Dr. Jerry Winkelstein, a pediatrician and specialist in primary immunodeficiency at Johns Hopkins in Baltimore, influential not only in the Boyle’s lives, but also in the birth of the Immune Deficiency Foundation.

“Dr. Winkelstein’s advice and assistance was immeasurable,” Marcia recalls. “We knew very little about certain aspects, but what we did know was that we wanted a strong national patient organization – not just a local one – that would seek successful partnering with the medical community and take a leading role in advocating on behalf of the primary immunodeficiency community.”

Once Dr. Winkelstein reached out to the medical community and began recruiting members of the fledgling foundation’s Medical Advisory Committee, the journey had begun. The Immune Deficiency Foundation made its debut in December 1980. “Seemed kind of silly to celebrate our anniversary last year,” Marcia laughs. “We were not even around for a month in 1980.”

Clarification, then, on why the organization will spend 2011 – instead of 2010 – touting its three decades of existence!

Marcia Boyle’s pride is palpable when she considers the thirty-years of accomplishments attained by the Foundation.

“We have created a voice for a community that didn’t have one,” Marcia says proudly. “And we created opportunities to help members of our community build a better life.”

Obviously gratifying, too, is IDF’s celebrated status as a preeminent source of information and educational materials; the irony of which can’t be lost given that a lack of then-available materials was the impetus for the founding of the organization.

“Not only were we the first U.S.-based foundation dedicated to primary immunodeficiency (and the second in the world), but our ‘Patient and Family Handbook’ was the first publication of its kind to be developed specifically for those whose lives have been affected by PIDD.”

While thirty years is – in calendar terms – a very long time, the period is but a blip on the generational stage; especially when the era spent confronting a chronic, sometimes devastating disease.

Still, she has no qualms about what has come before and the hard work that lies ahead.

“I accepted early on that things weren’t going to happen overnight,” Marcia says, “and in all, I think we have done very well. I find it amazing how we were able to grow – through physicians’ and nurses’ word-of-mouth early on, and later through the Internet. We have a strong network of support through our dedicated volunteers, medical community and our generous supporters who really make things happen!”

The IDF National Conference is an integral part of the foundation’s past and future growth. First held in 2001 – in cities such as Baltimore, Orlando and St. Louis – the paramount gathering is headed West in 2011, and landing at one of the most popular vacation destinations in the Southwest: the JW Marriott Desert Ridge Resort & Spas in Phoenix, AZ.

Recreational opportunities will abound – both on and off the sprawling, Desert Ridge grounds – but the real activities will take place in the meeting rooms and exhibithall. That is where world-renowned immunologists, skilled professionals, industry sponsors, dedicated volunteers and an exceptional patient population will come together from June 23 – 25 to learn, network, and share their experiences with people who understand what primary immunodeficiency is all about.

“Our National Conference is such an important event held for those patients and families touched by primary immunodeficiency disease. The entire event was developed with the needs of our community in mind.” Marcia says as our conversation draws to a close, “I would tell people that they owe it to themselves to join us in Phoenix and help strengthen the voice that IDF provides. Come celebrate IDF and our community!”

IDF is offering a Professional Medical Education Program in conjunction with our 2011 National Conference in Phoenix, Arizona. This course is for primary care physicians, family practitioners, pediatricians, allergists and immunologists who treat or may have an interest in patients with primary immunodeficiency disease. It is scheduled for Friday, June 24, 2011 from 11:00 am-5:00 pm at the JW Marriott Desert Ridge Resort and offers 4.5 AMA PRA Category 1 Credits™ for attendees. The pre-registration deadline is May 18, 2011. For more information, contact IDF at 800.296.4433.
New Immune Deficiency Foundation Publications Now Available!

Clinical Update in Immunoglobulin Therapy for Primary Immunodeficiency Diseases

The Immune Deficiency Foundation is pleased to offer a new Clinical Focus, Clinical Update in Immunoglobulin Therapy for Primary Immunodeficiency Diseases. This is the fourteenth Clinical Focus IDF has produced and as with past editions, it is designed specifically for healthcare professionals and focuses on topics relevant to primary immunodeficiency diseases.

Jordan Orange, M.D., Ph.D., Associate Professor of Pediatrics at the University of Pennsylvania School of Medicine, Division of Allergy and Immunology at The Children’s Hospital of Philadelphia authored this professional education monograph. He agreed that there would be tremendous value in developing a publication on the treatment of primary immunodeficiency with IgG and this piece would provide a timely opportunity to present physicians with appropriate guidelines, based on existing and new literature. This update focuses upon the currently available immunoglobulin preparations and how they can be used to optimize patient outcomes.

Special recognition goes to R. Michael Blaese, M.D., Consulting Medical Director of IDF, who served as the editor. This publication was made possible by an unrestricted educational grant from Baxter Healthcare.

Nuestro Sistema Inmunológico

The Spanish version of IDF’s popular Our Immune System storybook, Nuestro Sistema Inmunológico, is now available!

With Spanish being the second most common language in the United States after English, the need for the Spanish translation of this admired and universally used booklet was due! As with the original English version, this book educates children about primary immunodeficiency diseases through delightful, eye-catching illustrations. The characters explain how the immune system works and describe the treatments for pediatric patients. Children will understand their own bodies and be better prepared to deal with their own primary immunodeficiency.

Although this publication was originally written for children, it has been used as an educational tool for families, school personnel, healthcare providers and the public. It is necessary for all those who encounter a child with a primary immunodeficiency to understand the disease itself in order to prevent misconceptions and to understand the necessity of regular treatment and preventive measures. This publication was made possible by an unrestricted educational grant from CSL Behring.
Health Insurance Assessment Tips

For many people with a primary immunodeficiency, changing insurance companies or even just trying to understand what your current insurance plan will cover can be a challenge.

Before insuring your home, you take an assessment and inventory of all that you will need to cover. You should do the same for the health of yourself and your family.

The first step in the process is to ask yourself some general questions:

1) How comprehensive do I want coverage of health care services to be?
2) How do I feel about limits on my choice of doctors and hospitals?
3) How do I feel about a primary care doctor referring me to a specialist for additional care?
4) How much can I afford to spend on premiums?
5) How much of a co-pay or coinsurance can I afford to pay for my treatment?

Many times people look for lower premium policies only to find out that they must then meet a high annual deductible before the policy will start to pay for their medical expenses. It's also very important to know how much of a co-pay or coinsurance you will have for your medical expenses. Immunoglobulin replacement therapy (IgG) is very costly and if you have to pay 20%, 30% or even higher coinsurance for your treatment, is that something you can realistically afford to do?

When you have narrowed down your search of the type of insurance plan that you might purchase, the next step is to get answers to the following specific questions:

1) Will the policy cover a chronic or pre-existing condition or illness such as a primary immunodeficiency?
2) Is there a waiting period before a pre-existing condition or illness will be covered? If so, how long?
3) Is there a deductible? If so, how much is it?
4) Will the policy cover intravenous (IVIG) and/or subcutaneous (SCIG) treatment?
5) What Formulary Tier do they classify IG? (e.g. Tier 1, 2, or 4) The higher the Tier means more out-of-pocket expenses.
6) Is there a co-pay or co-insurance that must be paid for IVIG treatment? If so, how much is the co-pay or what is my coinsurance percentage?
7) Are there particular locations that I have to get my treatment? Do they differ based on whether it is SCIG or IVIG?
8) Does the policy have coverage if I want to get my IVIG done at home? Are nursing services and supplies associated with infusion, covered as well as the product cost for home infusions?
9) Are there any annual or sub limits within the policy?
10) What is the maximum out of pocket expense each year? (In other words, what is the most I will have to pay each year?).
11) Will the policy cover both an “in-network” and “out-of-network” provider, physician, and pharmacy? If so, what are the differences in cost?
12) For Medicare Insureds Considering a Supplemental Plan: What percentage of my IVIG treatment will the supplemental policy pay versus what will Medicare will pay?
13) Can I have a summary of benefits prior to purchasing or enrolling so that I can have all of this in writing?

Once you have answers to these questions, you will be armed with the information necessary to make a much more informed decision. The important thing is to have no surprises once the policy is in force and it’s time for treatment. It is stressful enough to manage a chronic medical problem. The peace of mind that comes with knowing you have a policy that you can afford, and one that will pay for the treatment at a level that you can afford, is worth all the upfront work in analyzing the right options for you and your family.
Last May 2010, Kathleen Sebelius, Secretary of Health and Human Service, announced that Severe Combined Immune Deficiency (SCID) would be added to the core panel of newborn screening conditions. Upon this momentous occasion, IDF launched the SCID Newborn Screening Campaign with the goal to have SCID added to the newborn screening panels across all 50 states.

The addition of SCID to the core panel of newborn screening conditions does not automatically necessitate that states begin screening for SCID. This panel consists of disorders for which the U.S. Department of Health and Human Services has recommended each state provide for mandatory newborn screening. It is imperative that we create the momentum to establish SCID newborn screening programs in all 50 states, as each state ultimately makes its own decisions about which conditions will be included in its individual newborn screening panel. SCID is the first new disease to be added to the federal uniform core screening panel by the evidence-based Committee review process.

**A little background on SCID**

Severe Combined Immune Deficiency (SCID) is the most serious primary immunodeficiency disorder. The defining characteristic of SCID is the absence of T-cells which leads to extreme susceptibility to serious illness. SCID has been characterized in the medical community as a pediatric emergency. If a baby with SCID receives a bone marrow transplant in the first 3.5 months of life, the survival rate can reach as high as 94 percent. However, the survival rate drops to less than 70 percent for infants who are transplanted after that age and continues to decrease as more time elapses. If undetected and untreated, SCID usually leads to death before the baby’s first birthday. The main causes for the drop in survival rate are serious infections undiagnosed babies with SCID developed prior to transplantation.

**IDF SCID Newborn Screening Campaign Activities**

To help raise awareness, IDF developed and launched the SCID Newborn Screening Campaign web page. The site offers background information on the campaign, as well as the IDF SCID Newborn Screening Advocacy Toolkit, an excellent resource for educating legislators and other policymakers. The web page hosts the IDF SCID Newborn Screening blog, which is designed to keep our community aware of volunteer activities and opportunities, as well as the status of state implementation of screening. Constantly revised, this blog keeps the community current on the latest state activity and opportunities for advocacy.

In August 2010, IDF conducted a survey of all state health departments to learn their process for adding SCID to the newborn screening panel. This way, volunteers who want to work in a particular state will have a sound starting point, including contact information for relevant policymakers.

September 2010 saw the development and distribution of the IDF SCID Live Rotavirus Vaccine Brochure designed to warn providers about the dangers of administering the vaccine to infants with SCID. This brochure, supported by IDF and SCID, Angels for Life Foundation, was produced at the behest of the Florida Department of Health; however, it can be used by any states that will not be able to implement screening immediately. The brochure was distributed to all pediatricians in the state of Florida, and continues to be given to other state health departments, physicians, and individuals.

Marcia Boyle, IDF President & Founder, presented to all 50 state laboratory programs in a meeting held by the Centers for Disease Control and Prevention (CDC) in October 2010. Marcia emphasized IDF survey data showing the improved outcomes for individuals with SCID who are diagnosed and treated early, as well as ways in which IDF can assist. Heather Smith, IDF volunteer and mother of a SCID patient, also presented her powerful story emphasizing the importance of early detection. Heather’s story – as well as one that is shared by Barb Ballard (a member of the IDF Board of Trustees and a SCID mom) can be found on the IDF SCID Newborn Screening Campaign website.

---

**Screenshot from Heather Smith’s Advocacy Channel video on SCID Newborn Screening.**
Looking Forward

IDF continues to lead the way on SCID newborn screening by holding meetings with state health departments, and by providing resources, data and references for expert immunologists in various states. A large focus of the IDF SCID Newborn Screening Campaign involves supporting volunteer activities in their states. Currently volunteers are working for SCID newborn screening in about 30 states! These volunteers are presenting at Newborn Screening Advisory Committee meetings, sharing their stories with state health departments, and raising awareness in the media and within the community.

The work of IDF volunteers has been incredibly successful with six state Advisory Committees voting to recommend SCID screening after presentation by IDF volunteers and staff – Delaware, Michigan, Minnesota, Rhode Island, North Carolina, Florida and Illinois.

With the help of IDF’s amazing volunteer advocates, as well as the perseverence and support of the community, the Immune Deficiency Foundation will continue to make universal SCID newborn screening one of our major priorities in 2011.

STATES AND TERRITORIES CURRENTLY SCREENING FOR SCID:
- California
- Puerto Rico
- Louisiana
- Texas*
- Massachusetts
- Wisconsin
- New York
  *Limited pilot program in select hospitals, screening ~20,000 of the states’ newborns

STATES WHERE NEWBORN SCREENING ADVISORY COMMITTEES HAVE VOTED TO RECOMMEND THE ADDITION OF SCID, BUT SCREENING HAS NOT YET BEGUN:
- Colorado
- Michigan
- Delaware
- Minnesota
- Florida
- North Carolina
- Illinois
- Rhode Island
- Iowa

ALMOST THERE – STATES THAT WE KNOW ARE CURRENTLY WORKING TOWARD ADDING SCID
- Connecticut
- New Jersey
- Georgia
- Pennsylvania
- Ohio
- Virginia
- Oregon
- Washington
- Nebraska

Resources

IDF SCID Newborn Screening website and Toolkit
http://www.primaryimmune.org/advocacy_center/scid/scid_newborn_screening_initiative.asp

IDF SCID Newborn Screening Blog
http://idfscidnewbornscreening.org/

IDF SCID Live Rotavirus Brochure
https://www.primaryimmune.org/advocacy_center/scid/scid_docs/LiveRotavirusVaccines.pdf

IDF Patient and Family Handbook, Chapter 5: Severe Combined Immune Deficiency

IDF SCID Video Stories
http://www.primaryimmune.org/advocacy_center/scid/scid_newborn_screening_initiative.asp

IDF Peer Support Networks
Cable Television Saves a Life

— by J. Doug Gill

While most people shy away from admitting how much time they spend watching television, Shelley Secemski has no problem telling you how important TV is to her: it literally saved her life.

“I truly believe that,” Shelley tells me during a recent phone conversation. “If it had not been for television I honestly believe I wouldn’t be alive today.”

After spending most of her adult life – particularly from her mid-30s to late 40s – hospitalized on numerous occasions for frequent illnesses, Shelley was spending another sleepless night in front of her TV set.

“It was about three o’clock in the morning,” she explains, “and I was lying there souped up on steroids or something and just scanning the channels when I saw an episode of ‘Mystery Diagnosis’.

The show, now in its tenth season, was in its infancy in 2005, and the story being told was what grabbed Shelley’s attention.

“Isaac’s Nightmare”, the fourth episode of the show’s first season, told the story of Isaac Antilla, a child who was literally born sick and spent the first five years of his life in and out of hospitals with pneumonia, bronchitis, gastro-intestinal issues and various infections before finally being diagnosed with Common Variable Immune Deficiency (CVID).

“As I’m watching Isaac’s story I’m saying to myself, ‘these are my symptoms… this is what I have’.”

Her doctor, however, wasn’t as convinced, and as was the case with all the physicians before him, was hesitant to entertain the possibility that Shelley had a primary immunodeficiency disease (PIDD).

“I had a number of doctors that truly believed I was crazy,” Shelley laughs, recounting the number of times she was sick and hospitalized. “So I told this doctor to humor me and insisted on getting the blood test.”

A week later the skeptical practitioner confirmed what “Mystery Diagnosis” had suggested: Shelley did indeed have CVID.

“I’m convinced I’d be dead,” Shelley states emphatically. “After all those years of being sick I was deteriorating rapidly.”

Six months of intravenous immunoglobulin treatment had a profound effect on Secemski’s quality of life, and after discovering subcutaneous treatments, she noticed an even more rapid improvement.

“It took about a year,” Shelley says, “but I felt like a brand new person.”

Anxious now to learn all she could about CVID, Shelley began the painstaking process of gathering information regarding her disease. It was then she discovered the Immune Deficiency Foundation.

“I was an IDF ‘follower’ for about a year,” she admits, and tells me she spent the time collecting IDF’s multitude of available literature and familiarizing herself with the Foundation’s website.

“I went to one of IDF’s regional meetings,” she says, “and I learned so much through the IDF experience that I knew I had to get involved – I had to tell my story to other PIDD patients, and give them the proof they need to never give up.”

Also cultivating her desire to volunteer was discovering that IDF’s Director of Education and Volunteer Programs is Kathy Antilla, mother of Isaac, the subject of the television program that saved her life.

Whether that connection was coincidence or fate can be left to those who debate such mysteries, because as far as Secemski is concerned her focus is on helping fellow patients and elevating the knowledge of PIDD in both the public consciousness and the medical community.

“Awareness, awareness, awareness,” Shelley reiterates. “And I can – god-willing – get that message out through telling my story, not only to patients but also to doctors and nurses.”

Secemski knows that her advocacy – and personal story – can help change not only people’s lives, but also their perceptions. If so, it seems to be the only reward she seeks.

“The more that people become aware of patients and families that are affected by primary immunodeficiency disease,” Shelley concludes, “the more I feel that all of my angst and suffering will not have been for nothing.”

To watch the Mystery Diagnosis episode “Isaac’s Nightmare”, visit http://idfcommunityinaction.org/2011/03/24/pidd-mystery-diagnosis.
FROM MARCIA'S KITCHEN TABLE

In Celebration of our Anniversary

IDF is delighted to announce a new giving club called “Marcia’s Kitchen Table.” Thirty years ago, Marcia Boyle was a concerned young mother who, like all parents, wanted the best for her son. He had been diagnosed with a primary immunodeficiency disease (PIDD) and she was struggling to care for him. Unfortunately, at that time, she found very little information or guidance about his disease. Something had to be done! So, along with other families of children with PIDD and some dedicated physicians, they banded together to create the Immune Deficiency Foundation to help fill the needs of this small, but growing community.

In the early days, much of the time developing and establishing IDF took place at Marcia’s kitchen table. No one ever imagined that, from those humble beginnings, IDF would grow into the vibrant, active organization it is today.

In honor of this important milestone in IDF’s history, we have established a new giving club, “Marcia’s Kitchen Table,” for those who give $300 or more. We hope you will join Marcia at her “kitchen table” and reaffirm your commitment to keep IDF strong by making a contribution today! Visit our website at www.primaryimmune.org or call us at 800.296.4433 to make a gift, or simply use the giving envelope in this newsletter. Here’s to another 30 years!

THINK ZEBRA! Silent Auction

At the IDF 2009 National Conference, IDF hosted the first-ever THINK ZEBRA! Silent Auction. Our community embraced the event and donated more than 150 items! The auction was extremely popular and greatly contributed to the success of the weekend.

Plans are underway for the Second THINK ZEBRA! Silent Auction to be held at the IDF 2011 National Conference in Phoenix.

Please support this endeavor with the donation of an auction item. We’ve provided a few ideas below, and hope you will consider an imaginative contribution.

- Autographed sports or entertainment memorabilia
- An autographed script of a popular television show, or VIP tickets for a backstage tour or to watch a taping
- Other ideas – get creative!

Donations are tax-deductible as allowable by law, and all auction proceeds will directly benefit IDF’s mission. In appreciation of this support, donors’ names will be recognized in the Silent Auction program and displayed with the item at the auction. If you would like to donate an item or have questions, please contact Allison Mayberry, Director of Development, at amayberry@primaryimmune.org or 443-632-2555. Please include a description of your donation, an estimated value, and how you would like to be recognized.

See you in June!
**Biotest submits Bivigam™ dossier for regulatory approval to US Food and Drug Administration**

Biotest Pharmaceuticals Corp., Boca Raton, Florida - USA, has submitted the dossier for regulatory approval of the polyspecific immunoglobulin Bivigam™ to the US regulatory agency FDA (US Food and Drug Administration).

Bivigam™ is a polyspecific immunoglobulin for the treatment of antibody deficiencies. The product is a ready for use 10% solution, stabilized by glycin and therefore sugar-free. This is a considerable advantage for the clinical application. This preparation was developed exclusively for the US market. In Europe and other global markets, Intratect® will continue to be marketed.

The submission of the dossier for regulatory approval of Bivigam™ to the FDA marks an important step for the expansion of the US presence of Biotest. Biotest expects the approval of Bivigam™ for the end of 2011.

Excerpted from Biotest Pharmaceuticals Corp. news release November 3, 2010.

**Grifols Announces US Launch of Flebogamma® 10% DIF IVIG**

Grifols announced availability of its recently approved Flebogamma® 10% DIF intravenous immune globulin. Grifols is a global healthcare company specializing in bioscience medicines derived from human plasma. Approval from the US Food and Drug Administration (FDA) for Flebogamma® 10% DIF was obtained in July 2010 and approval in Europe is expected before the end of the year. Today’s announcement signals widespread product availability to the US market.

The approval and launch of Flebogamma® 5% DIF in early 2007, ushered in a new standard in IVIG treatment with the development of a dual inactivated, nano-filtered (DIF) product. Like Flebogamma® 5% DIF, the new 10% solution has two distinct pathway inactivation processes (heat treatment and solvent detergent) and a proprietary 20 nanometer filtration step. The manufacturing process for Flebogamma® DIF is also very efficient at eliminating extraneous proteins, resulting in a high purity IVIG solution (99.4% IgG).

Like all Grifols’ products, each vial of Flebogamma® 10% DIF is laser etched with a unique identification number to ensure product integrity. In addition, the outer packaging is secured with a tamper evident holographic overseas containing specialized printing to confirm authenticity. Grifols also offers healthcare providers access to a proprietary web-based system called Pedigri® that provides full traceability for every plasma donation used to produce an individual product vial.

Excerpted from Grifols news release Nov. 22, 2010.

**CSL Behring Receives FDA Approval to Extend Shelf Life of Hizentra® to 30 Months**

CSL Behring announced that the U.S. Food and Drug Administration (FDA) has approved a supplemental Biologics License Application (sBLA) to extend the shelf life of Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid, from 24 months to 30 months. Hizentra, the first and only 20 percent subcutaneous immunoglobulin (SC Ig) approved in the U.S., is the only SC Ig in the U.S. that can be stored at room temperature throughout its entire shelf life.

Hizentra is indicated for the treatment of primary humoral immunodeficiency (PI). PI is a group of disorders, usually genetic, that result from a dysfunctional immune system. This condition prevents patients from fighting off infections caused by common germs.

Stabilized with L-proline, a naturally occurring amino acid, Hizentra can be stored at room temperature (up to 25°C [77°F]) for up to 30 months. Because no refrigeration is necessary, Hizentra is always ready to use without warming, offering patients and physicians convenience and portability.

Hizentra with 30-month shelf life packaging is expected to be available later this year. Current Hizentra patients are encouraged to contact their physician with any questions regarding the shelf life of their current supply.

Excerpted from CSL Behring news release, February 24, 2011.

**Grifols Expands its PatientCare Program to Address Insurance Lapses in the Primary Immune Deficiency Community**

Grifols, Inc. announced that it has expanded the company’s PatientCare Program to offer immune globulins (IVIG) to the Primary Immune Deficiency community (PID). The program will provide Flebogamma® 5% DIF (Immune Globulin Intravenous (Human)) or Flebogamma® 10% DIF (Immune Globulin Intravenous (Human)) at no cost to patients with PID when insurance coverage is not available. The PatientCare Program consists of Grifols Assurance for Patients (GAP), which provides therapy for users of Grifols’ products during a lapse in insurance coverage, and Grifols Patient Assistance (GPA), which provides therapy for individuals in need of temporary assistance.

To take advantage of the program, a few simple forms must be completed and sent to a Grifols PatientCare representative for verification. The GAP program is open to anyone diagnosed with PID who has used a Grifols’ product for the three months prior to lapse in coverage. The Patient Assistance program is open to anyone diagnosed with PID without insurance who is in need of temporary assistance regardless of whether they have previously used a Grifols therapy.

Applicants of the GPA program must meet financial eligibility requirements and both programs require certain insurance ineligibility. The GAP and GPA programs are not emergency programs and if a lapse in insurance coverage is anticipated, the eligibility forms should be completed ahead of time. Grifols also operates an Emergency Supply System for physicians seeking to obtain IVIG to treat a specific patient under emergency circumstances. Access to Grifols’ Emergency Supply System does not require the requesting physician to be a current customer of Grifols – there are no prerequisites to the program other than an emergent need for treatment of a specific patient.

Excerpted from Grifols news release February 3, 2011.
Immunoglobulin Manufacturers’ Assistance Programs

Baxter Healthcare - www.baxter.com - 800.422.9837
Products: Gammagard S/D, Gammagard
Programs: GARDian Program and Reimbursement Assistance
The GARDian Program is a no-cost comprehensive resource, open to all people with primary immunodeficiency, their families, and anyone who relies on immunoglobulin therapy including assistance with lapse in insurance coverage.
(877.655.4273 - https://www.mygardian.com/gardian/home)

CSL Behring - www.cslbehring.com - 800.683.1288
Products: Carimune NF, Hizentra, Privigen, Vivaglobin
Programs: Reimbursement Answer Line and Patient Assistance Program
Reimbursement Resource Center is designed to provide helpful insights for understanding medical service costs and related insurance matters, including health insurance reimbursement for the CSL Behring product line and Patient Assistance Program.
(800.676.4266 - http://www.cslbehring-us.com/patients-and-families/reimbursement-resources-center.htm)

Grifols USA - www.grifolsusa.com - 888.GRIFOLS
Products: Flebogamma 5% and 10% DIF
Programs: Assistance Program Reimbursement Support
Grifols Reimbursement Support provides health insurance reimbursement assistance for Grifols products including a resource Website, an emergency access program, and a reimbursement hotline.
(888.GRIFOLS, option 4 -http://www.grifolsusa.com/reimbursement.html)

Octapharma - www.octapharma.com - 201.604.1130
Products: Octagam
Programs: Compassionate Use Program
Octapharma USA has a limited compassionate use program for patients with a primary immunodeficiency who experience a temporary lapse in product coverage.
(201.604.1123 - stanley.ammons@octapharma.com)

Talecris Biotherapeutics - www.talecris.com - 800.243.4153
Products: Gamunex-C
Programs: Gamunex Connexions
Gamunex Connexions provides support for Gamunex-C patients with patient education and resources including assistance in the event of private insurance lapse.
(888.263.8243 - https://www.gamunexconnexions.com/)

These donations help IDF to 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 Web site, 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

With Gratitude
Honorary and Memorial Gifts – 10/15/10 to 2/15/11

Gifts in Honor Of:
Courtney Abrams
Robin and Jim Abrams
Curtis Anderson
Greg Anklam
Isaac Antilla
Barb, Don, and Ray Ballard
Daniel Benchek
Nathan Burdick
Steven Chester
Tom Crugnale and his grandson
Jonathan Bene
Dr. Charlotte Cunningham-Rundles
Amanda Davis
Tyler and Riley Dietz
Noelle Drews
Emily Ernst
Landon Feniger
Larry Feniger
Laurel Feniger
Laurence Feniger
Michael Feniger
Ronald Feniger
The Fenton Family
Amanda Flood
The Fox Grandsons
Hannah Giclas
Laura Guenther’s birthday
Tara Guetz
Karen Rubin-Jablo and John Jablo
David Jednorski
Eileen Lackey
Larry LaMotte
Ashton Lentz
Scott Leonard, Marketing Arts
Jon Lombardo
Tracey Malloy
Thomas David Marbach
Dr. Lloyd Mayer
Michael and Myra Marranzino family
Renato Marranzino
George Martin MD
Dr. Lloyd Mayer
Dr. Deborah McCurdy
Trace Meadows
Claire Menzer
“Little Larry” Neumann
Jenny Peckenpaugh
Brian Rath
Michael and Stephanie Reiss
Dr. Robert Roberts
Cole Romeo
Stephanie Rosenthal
Dianne Schachner’s Birthday
Christian Scheiffele
Thomas R. Smith
Cheryl and Greg Spinazze/Jacob Main
Wayne and Judy Stein
Max Steiner
Jodi Taub

Gifts in Memory Of:
Elizabeth Bald
Lillian Braun
Thomas Crugnale
Joseph Dellorso
Dolores Drew
Rev. Ruth Louise Hanks
Fred Hensle
Erik Hurley
Arline Jares-Sekerak
Betty Dunsmore Klement
William E. Leonard
Beatrice Malone
Tom Marbach
Eric Marder
Kristin Martin
Evelyn Maselli
Chris Meddaugh
Dominick Passalacqua Jr.
Will Pesek
Brenda Redmond
Rachel Roy
Reade Shook
Marcela Sim
Lawrence Hunter “Larry” Stewart
Arian Sprague
Judith Stoll
Cheryl Teetsle
Thomas “Caleb” Walker
Gary Weber
Elaine Wettstein
Kimberly Williams
For an updated IDF Calendar of events, visit
www.primaryimmune.org/idfcalendar.