It was the mid-1980s and Sara LeBien accompanied her husband Bob from California to the IDF Board of Trustees meeting in Baltimore. Jerry and Marilyn Winkelstein were presenting the first edition of the Patient and Family Handbook on Primary Immune Deficiency Diseases and the board members were thrilled with finally having a comprehensive resource book for the primary immunodeficiency community. Congratulations were shared around the table and plans were quickly put into place for distribution of the publication to patients and their families.

“What about the children?” Although Sara was delighted with the Handbook, as a mother of a son with a primary immunodeficiency and a primary school teacher, she couldn’t help but think, “What about the children?”

It was a long flight from Baltimore to southern California, and Sara is not the kind of person to waste time. She started writing a story about how the immune system works and what happens when there is a primary immunodeficiency disease.

“I wanted a story for very small children and didn’t want it to be too medical or scary. I wanted to create a story that children could easily understand and relate to.”

continued on pg.2.
Update Your Contact Info
If you are a patient, and you have not updated your IDF contact information, now is the time! IDF will keep you informed of the latest news regarding treatment, education, recalls and public policy issues.

Please visit www.primaryimmune.org to complete the electronic form or give us a call at 1.800.296.4433 for a hard copy form.

Continued from pg. 1.

Sara laughed, “While on the plane, I even started sketching little medical pictures and the woman sitting next to me wanted to know if I was a doctor!”

Sara’s beginning efforts resulted in the first edition of Our Immune System in 1990. This is a simple story of how the immune system works and the treatments necessary for children with primary immunodeficiency diseases. Through delightful illustrations, the story is told by friendly characters in the immune system — B-cells, T-cells, and even phagocytes. Reviewed by physicians, teachers, nurses, psychologists, and parents, hundreds of thousands of copies have been distributed; in fact, it continues to be the most requested publication from the IDF national office. In demand worldwide, IDF has given permission to have it translated into eight languages.

New Second Edition of Our Immune System
However, over the years, it became clear that Our Immune System needed a little updating. Since 1990, new treatment options have been approved, technology has changed and our audience has become more diverse. Recognizing the need to reflect these changes, IDF knew whom to turn to—it wouldn’t be Our Immune System without Sara LeBien! Her sensitivity and gentle story telling demystifies the treatments children with primary immunodeficiency face and better prepares them for what to expect. With Sara’s guidance, IDF is proud to announce the availability of the second edition of Our Immune System.

New information has been added, colorful illustrations and modern characters inhabit the pages. The illustrations aid the reader in understanding how the immune system functions with the help of B-cells, T-cells, phagocytes and complement. The story helps children understand their own bodies and what happens to them when they get sick. Our Immune System describes the basic components of the immune system and how they function, and what happens when children get an infection. Even complicated treatments, like intravenous immunoglobulin infusions (IVIG) or subcutaneous immunoglobulin (SCIG) are simply explained.

Although this publication was originally written for children, it has been used as an educational tool for families, school personnel, healthcare providers and the general public. It is necessary for all those who come into contact with 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.

Our Immune System was made possible by an unrestricted educational grant from IgG America and ASD Healthcare.

Our Immune System is available free of charge by contacting 800.296.4433 or idf@primaryimmune.org. It is also available on the IDFWeb site, www.primaryimmune.org.
NOW AVAILABLE

Clinical Focus Publication about Subcutaneous IgG

IDF is proud to offer the new issue of *Clinical Focus on Primary Immune Deficiencies*. This professional education monograph focuses on Subcutaneous IgG Therapy in Immune Deficiency Diseases and was authored by Dr. Melvin Berger, edited by Dr. Kathleen Sullivan and Dr. R. Michael Blaese acted as series editor.

Beginning with a brief history of IgG treatments, this publication highlights the Pharmacokinetics of IgG Administered by the IV and Subcutaneous Routes, Regulatory Issues Surrounding Licensing of Subcutaneous IgG in the U.S., Adverse Events Associated with Subcutaneous Administration of IgG and Developing Individualized Treatment Regimens.

Clinical Focus is designed specifically for healthcare professionals and was made possible by an educational grant from CSL Behring. To receive a free copy, please contact IDF at 800.296.4433 or e-mail your request to idf@primaryimmune.org.

New IDF Discussion Forum Unveiled

We’re pleased to announce the debut of our new IDF Discussion Forum that has replaced our old discussion forum at the same location on our site -- http://www.primaryimmune.org/forums/forum_intro.htm.

We are excited about the new features of our forum that include: a calendar of events; a private messaging system—which enables participants to send private messages to each other; RSS feeds—which helps users keep up with new forum posts in an automated manner that’s easier than checking them manually; emoticons—which are a combination of symbols used to convey emotions; anti-SPAM tools; member profiles; a powerful search engine; and much more!

The forum is designed for you to share experiences and offer understanding to others with primary immunodeficiency diseases. The messages on the forum are posted by individuals affected by primary immunodeficiency diseases. The information should not be used in place of a visit, consultation, or advice of your physician. Should you have any health care related questions, please call or see your physician.

The new forum features the following topics: Living as an Adult with Primary Immunodeficiency; Parenting a Child with Primary Immunodeficiency; Experiences with Immune Globulin Therapy; Coping with a New Diagnosis; Teens Living with Primary Immunodeficiency; Insurance Issues; and Forum Suggestions. We urge you to review the topics, discuss your experiences, ask questions, make suggestions and share your ideas. And most of all, participate in your areas of interest. This is the first stage of our IDF Web site redesign, so look for new features in the coming months!

Plan a Blue Jeans for Healthy Genes Day

Host a Blue Jeans for Healthy Genes Day at work, school or other organization in your community. It is a simple and powerful way to raise awareness of primary immunodeficiency diseases, while raising funds for further research and patient programs.

Order your free Blue Jeans for Healthy Genes kit to get started. Contact IDF at 800.296.4433, or e-mail Kantilla@primaryimmune.org for more information.
METHICILLIN-RESISTANT STAPHYLOCOCCUS AUREUS (MRSA) GUIDANCE TO PATIENTS WITH PRIMARY IMMUNE DEFICIENCIES

Frank R. DeLeo, Ph.D.¹ and Harry L. Malech, MD²

¹Laboratory of Human Bacterial Pathogens, Rocky Mountain Laboratories, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Hamilton, MT

²Laboratory of Host Defenses, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, MD

This work by Frank R. DeLeo, Ph.D. and Harry L. Malech, M.D. was supported by the intramural program of the National Institute of Allergy and Infectious Diseases, National Institutes of Health, DHHS.

Background

Methicillin-resistant Staphylococcus aureus bacteria, often referred to as MRSA, has become a significant infection problem both in hospitals and in the general community. It is a type of staph that is resistant to methicillin and other commonly used antibiotics in the same class, including penicillin, amoxicillin, and oxacillin. While MRSA is of concern to everyone, patients with a variety of primary immune deficiencies (PID) may be at increased risk for at least three important reasons. First, depending on the kind of PID, some patients may be less capable of defending against infection with either regular Staphylococcus aureus (S. aureus) or with MRSA. Second, patients with PID in frequent contact with hospitals and other general health care institutions may have a somewhat increased risk of coming in contact with other individuals who are carriers of, or infected with, S. aureus including the MRSA variety. Third, patients with some forms of PID may have eczema or other skin conditions which enhance the tendency to become colonized with S. aureus including the MRSA variety.

Understanding MRSA

To understand the significance of MRSA, it is necessary to know some general information about all S. aureus. Regular everyday S. aureus has been a cause of severe infections in humans for thousands of years. It is a very ancient and durable human pathogen. Even in the antibiotic era of 1950’s to the present, S. aureus has remained a problem and a concern despite the increasing availability of many types of antibiotics that can effectively kill this bacterium. It is important to know that it is very common; in fact, it is the rare person who has not had a S. aureus boil or other infection. It is not unusual for perfectly healthy people to be colonized in their nose with S. aureus. These people comprise the most common source of the bacteria (including the MRSA varieties) in the community. S. aureus, including MRSA varieties, can survive and infect through inanimate damp objects such as dirty towels and shared sports equipment. However, it is most effectively and commonly spread through direct hand and other skin contact with these carriers, as well as by individuals who have actual infections.

The first isolated examples of MRSA were found in hospitals where they caused infections only in very debilitated surgical or hemodialysis patients. It was initially thought that these early hospital-associated MRSA strains were both antibiotic resistant and particularly infectious. However, studies in the past few years indicate that it is actually the community-associated MRSA strains, capable of easily infecting healthy individuals that are more infectious. These community-associated (CA) MRSA strains are very infectious and tissue destructive. They cause outbreaks in the general community of healthy individuals in schools, sports teams, gymnasiums and other settings where there is close physical contact. These CA-MRSA strains actually are genetically distinct from the strains causing infections in debilitated hospitalized patients, and appear to have unique genetic factors that allow them to more effectively infect, spread and cause injury in people with perfectly normal immune systems. This ability to easily infect, spread in the body and cause tissue damage is what is meant by saying an organism is more virulent. It is this greater virulence of these CA-MRSA strains that is the major problem causing the current epidemics and severe infections among otherwise healthy individuals. The antibiotic resistance makes it harder to treat and adds to a high level of anxiety. However, it is not the only concern and is not the main reason that CA-MRSA infections has caused epidemics in the schools, among sports teams, and in long term care institutions.

Guidance for Patients with Primary Immune Deficiencies (PID)

The concern about CA-MRSA in schools, day care centers, sports teams, and health care institutions affects everyone and not just patients with PID. In addition, health care institutions are experiencing problems not just with MRSA but with resistant and virulent strains of a number of other types of bacteria. This has led to increased diligence of hospital epidemiologists in isolating patients with suspect infections and increased training of physicians to be thinking about and recognizing potential problem bacterial infections. Recognition and treatment of health-care workers who may themselves be carriers of resistant bacteria has been
improved, and training of physicians to liberally use germicidal hand
washes and vigorous hand washing with soap and water has been
amplified.

Even for the general populace, early attention to boils and other
skin infections, use of germicidal lotions, and frequent hand
washing can do much to reduce the spread of S. aureus including
MRSA strains. At schools and day care centers, and with sports
teams, the sharing of personal items of clothing or equipment
should be discouraged. Germicidal hand lotions should be available
and encouraged, as should hand washing. Very hot water cycles
and bleach should be used in the laundering of any shared towels
or similar items.

In busy, active institutions such as schools, it is neither practical,
nor cost effective to have janitors disinfect doorknobs or multiple
user desks through the day. However, showers and sports
changing areas are special places where frequent attention to
cleanup and use of diluted bleach or other disinfectant may help
reduce spread of MRSA. Institutions should make antiseptic
cleanser gels more available in a variety of locations so that
students use them routinely. Sinks should have pump soaps and
not bar soaps available for hand washing. In general S. aureus is
spread by contact — it does not come from the floor or on dust
to infect someone, but rather is spread through direct contact. It
is usually contracted by hand contact, such as touching an infected
individual or coming in contact with their personal items that they
have recently used.

Patients with PID (depending upon the specific type of PID)
may be less capable of defending against infection with S. aureus
including the MRSA strains. They may also have frequent contact
with hospitals and other general health care institutions where
they may be at increased risk of coming in contact with other
individuals who are carriers of, or infected with, S. aureus including
the MRSA varieties. Patients with PID who have eczema or other
skin conditions causing breaks allow for enhanced colonization
and infection with S. aureus including the MRSA varieties. Nasal or
skin carriage with S. aureus including MRSA varieties is so common
in the general populations that generally it is impractical to do
routine testing and treatment for carriers. However, in the case
of patients with PID, particularly patients who are thought by their
physicians to have a type of PID or associated skin condition that
makes them more at risk from S. aureus, it may be cost effective to
periodically test the patient for carriage. For young children with
PID, it may even be reasonable to periodically test their primary
care givers to see if they are carriers of S. aureus because of the
frequent intimate contact between caregiver and child with PID.
There are no studies that provide clear guidance with respect to
this, but with some types of PID relationships have been observed
between carriage and later infection with the same organism.
Thus, treatment of or prevention of nasal carriage by use of nasal
application of mupirocin ointment may be reasonable in some
cases. On a case by case basis that must be determined by the
patient’s physician, it may be reasonable to consider treatment to
try to eradicate S. aureus carriage in a PID patient or young child
PID patient’s primary caregiver.

The parents of some children with PID have become concerned
about even sending their children to school at all because of the
new anxiety raised by the CA-MRSA epidemic. This is a complex
decision that does not lend itself to a simple answer that will cover
every situation. It should be emphasized that most children with
a primary immunodeficiency disease are able to attend school
safely. The exposure risk for all pathogens, not just CA-MRSA,
is somewhat greater for children attending school than those
who are home schooled and who also avoid all other contacts
with groups of children. In some unusual special instances, home
schooling, homebound and even dual enrollment options may be
viable alternatives. However the social, psychological and learning
benefits to the child enrolled in a general school environment
must remain an important part of the equation when considering
one’s options. The child’s physician can help in making this decision,
but as a general rule, if children have no restrictions on being in
public places, such as movies, malls, and airplanes, they should be
able to safely attend school. If it has been determined that school
is ordinarily a safe environment for a specific patient, it is usually
not advisable to stop schooling because of the current CA-MRSA
epidemic, but rather to take the additional precautions outlined
above and continue to attend school. The option of requesting
that the child be excused from participating in physical education
(PE) classes might be considered depending on the type of
activities scheduled for those classes.

For additional information in scientific language with
references about MRSA, please visit the IDF Web site at
www.primaryimmune.org
Biomat “Hangs-up” Jeans for Dollars and Euros!

Biomat USA Plasma Centers, owned by Grifols, embraced the IDF Blue Jeans for Healthy Gene’s “Hanging up Jeans” program in 2007. This program creates awareness about primary immunodeficiency diseases and raises funds for IDF by offering small cut-out pairs of paper jeans for a donation. The jeans are signed by their “sponsor” and are displayed throughout the centers.

All of the 58 plasma centers nationwide welcomed the program and many center staff members even created additional ways to generate excitement and additional funding by organizing special events during this time. At the end of the program, the donors and employees at the Biomat USA Plasma Centers contributed over $75,000. To raise the stakes even higher, Grifols generously made the commitment to match every dollar raised by “Hanging up Jeans” with one Euro.

Shinji Wada, President & CEO of Biomat USA, stated, “The Blue Jeans for Healthy Genes program gave our employees and donors a remarkable opportunity to recognize the value of donating plasma. The benefits to them both in terms of motivation and renewed commitment to donating has been tremendous. This program has been a real win-win situation for both IDF and Biomat USA.”

Marcia Boyle, President & Founder of IDF added, “We are thrilled with the successful efforts of the Biomat USA Plasma Centers. Their commitment to our Blue Jeans for Healthy Genes program has not only raised a great deal of money, but

has helped donors, staff and the community gain a broader understanding of primary immunodeficiency diseases. We hope that plasma donors and staff now realize that their efforts of donating and collecting plasma are lifesaving to persons with primary immunodeficiency.”

If you would like to learn more about IDF Blue Jeans for Healthy Genes and in particular, the “Hanging up Jeans” program, please contact Kathy Antilla at kantilla@primaryimmune.org or 763.444.6840.

Girl Scout Hosts Plasma Drive

The Girl Scout Bronze Award recognizes a girl’s commitment to excellence as she develops skills and values to meet present and future challenges in her life. To earn the award, she must design and carry out a plan of activities to show her promise to help others, improve her community and world, and become the best she can be.

Abigail Stills, left, and cousin Jadon Pennington show off the plaque awarded Abby.

Abigail (Abby) Stills, a member of Girl Scout Troop 227 in Owasso, Oklahoma, recently received this recognition. To complete the requirement for volunteer community service, Abby held a plasma drive with ZLB Plasma Services. Her cousin Jadon Pennington, also a Girl Scout, has had primary immunodeficiency since she was born, eight years ago and requires regular plasma treatments.

Abby knew that hosting a plasma drive would not only help Jadon, but also help other people who needed plasma based treatment. Abby’s goal was to bring 100 donors to ZLB. She posted fliers in banks, businesses and handed them out to individuals. In one month, Abby surpassed her goal by almost 250%, bringing ZLB 243 donors! Several donors even made a commitment to continue donating for at least six months. Thanks to her superb marketing and determination, Abby has made an enormous impact on her community.

Abby has an ongoing interest in the plasma drive project and she continues to raise awareness of the need for plasma. IDF congratulates Abby and her proud parents Kristi and Christopher Stills for this outstanding achievement.
**INDUSTRY NEWS**

**CSL Behring Announces FDA Approval of Privigen™—First Proline-Stabilized 10 Percent Liquid IVIg—and will launch in the first quarter of 2008**

CSL Behring announced that the U.S. Food and Drug Administration (FDA) has granted marketing approval for Privigen™ (Immune Globulin Intravenous (Human), 10% Liquid), an intravenous immunoglobulin (IVIg) for treating patients diagnosed with primary immunodeficiency (PI). Privigen™ is also indicated for the treatment of chronic immune thrombocytopenic purpura (ITP) to rapidly raise platelet counts to prevent bleeding. A 10 percent liquid preparation of polyvalent human immunoglobulin, Privigen™ offers healthcare professionals convenience and ease-of-use. It is the first and only proline stabilized IVIg that is always ready for immediate use, requiring no refrigeration or reconstitution.


**Grifols successfully concludes the transition to its new intravenous immunoglobulin, Flebogamma® DIF in the United States**

The new plant in Barcelona is the site of the manufacturing facilities for Flebogamma® DIF for the US market and will eventually take on production of this new generation product for Europe and other markets.

The new generation IVIg was very well received in the United States and the transition was completed in record time (having begun in June 2007). The Flebogamma® DIF production plant in Barcelona, approved by the FDA in December 2006 and the EMEA in August 2007, will also manufacture this product for other markets once the regulatory processes are completed for each country. The company plans on completing the transition to Flebogamma® DIF on the European market, most likely beginning with Germany, in 18 months time.


**Talecris Announces New Hypermune™ Product Safety Advances**

Latex-free vials and syringes and new FDA-approved pathogenic prion removal labeling demonstrate ongoing Talecris commitment to providing safest possible protein therapies.

Talecris Biotherapeutics, Inc. announced that as of October 1, 2007, all new releases of its line of Hypermunes™ (hyperimmune globulin therapies) are latex-free. With the elimination of latex from the vial rubber stoppers and prefilled syringes, physicians can confidently use Talecris’ Hypermunes in their patients with latex allergy.

Talecris is the only manufacturer with a full line of hyperimmune products including HyperRHO™ S/D (Rho (D), Immune Globulin [Human]), HyperTET™ S/D (Tetanus Immune Globulin [Human]), HyperRAB™ S/D (Rabies Immune Globulin [Human]), HyperHEP B™ S/D (Hepatitis B Immune Globulin [Human]), and GamaSTAN™ S/D (Immune Globulin [Human]).

*Excerpted from Talecris News Release, October 2, 2007.*

**Device Recall - Heparin and Normal Saline Pre-Filled Flushes**

AM2 PAT, Inc., Angier, North Carolina, initiated a nationwide recall of all lots of both Heparin and Saline pre-filled flushes manufactured by AM2 PAT. These products are distributed under two brand names, Sierra Pre-Filled Inc. and B. Braun. These products are sold in 3ml, 5ml sizes for Heparin and 3ml, 5ml and 10ml sizes for Normal Saline. Both products are sold as pre-filled syringes. One lot under recall of this product 1003-02, Lot 070926H, Heparin IV flush syringes has been found to be contaminated with Serratia marcescens, which has resulted in patient infections. CDC has confirmed growth of Serratia marcescens from several unopened syringes of this product.

This type of bacterial infection could present a serious adverse health consequence that could lead to life-threatening injuries and/or death. Consumers and user facilities that have any of these recalled pre-filled syringes, Heparin or Saline Lock Flush Solution USP, should stop using the product immediately. These products should be immediately quarantined in your inventory and returned to your distributor immediately.

*Excerpted from FDA Web site, January 18, 2008.*

**Octagam Withdrawal**

Octapharma USA Inc. has initiated a voluntary withdrawal of one lot of Octagam (Lot A732B8431). They are advising customers not to administer any product from the lot being withdrawn. No other lots of Octagam are affected by this recall. Octapharma is taking this voluntary action based on several reports related to non life-threatening allergic type skin reactions in connection with this lot.

Product: Octagam [Immune Globulin Intravenous (Human) 5%]
Lot Number: A732B8431
Expiration Date: August 2009

*Excerpted from the FDA Web site, December 24, 2007.*

**Sign up for the IDF E Newsletter!**

Visit www.imakenews.com/idf
“Is it just an infection?” posters are popping up all over the U.S. These colorful posters caution people to be suspicious if they have an infection that is recurrent, persistent, severe, unusual, or if it runs in their family. If any of the symptoms persist, people are encouraged to ask their physicians to check for the possibility of a primary immunodeficiency disease — emphasizing the importance of early diagnosis and proper medical care.

Volunteers across the nation have been creative in helping spread awareness about primary immunodeficiencies—

Jessica Gilbert, a nurse and IDF volunteer in Nashville, Tennessee reports “The latest and greatest place that I have used the posters at is my pharmacy. I leave some at the counter and in the waiting area. It works like a charm.”

In Carrollton, Texas, volunteer Lucy Toye displays the posters at her church’s blood drive.

Frank Meuers, a teacher and a new volunteer in Plymouth, Minnesota told us, “I put the poster up in the nurse’s office at my school. Many parents come in to pick up sick kids, and I thought this was a perfect location.”

Hailing from New York, New York, Bill Hindin, longtime volunteer, took the poster to work. “I was able to have the personnel department where I work put it up on the lunch room bulletin board. I also included my IDF volunteer card on the poster. I am also getting approval to put the poster up on the bulletin board in the lobby of my building.” Bill added, “The next time I go to my doctor, I will ask him to put it up in the office. It is a terrific eye-catching poster. Great work!”

Our volunteer Diane Mato in Elmhurst, Illinois has been busy exhibiting at health fairs in the Chicago area. She has even enlarged the “Is it just an infection?” poster for better visibility.

April is Primary Immunodeficiency Disease Awareness Month

With Primary Immunodeficiency Disease Awareness Month in April, it is the perfect time for you to become involved and help educate others about these disorders.

We want you to help spread awareness by using this poster. We have made it as easy as possible — simply cut the next page out and take it to some place in your community. The colorful posters are perfect for bulletin boards in physician offices, schools, or other public places that will catch the attention of passersby.

If you want more, simple call 800.296.4433 or e-mail idf@primaryimmune.org.

Let us know of your activities and success with promoting awareness. Remember, the flyers alert individuals about the possibility of a primary immunodeficiency and your efforts might help save a life!
Is it just an infection?
You should be suspicious if you have an infection that is...

**Recurrent**
keeps coming back

**Persistent**
won’t completely clear up or clears very slowly

**Severe**
requires hospitalization or intravenous antibiotics

**Unusual**
caused by an uncommon organism

**Runs in the Family**
others in your family have had a similar susceptibility to infection

If any of these describe your infection, ask your physician to check for the possibility of a primary immunodeficiency disease. These diseases are caused by genetic defects and can affect anyone, regardless of age or sex. People with primary immunodeficiencies are more susceptible to infections and health problems that lead to serious and debilitating diseases. It is critical to get an early diagnosis and proper medical care.

**IDF Can Help**
Immune Deficiency Foundation (IDF) is the national organization dedicated to patients living with primary immunodeficiency diseases. Contact IDF to learn more.

800.296.4433 • idf@primaryimmune.org • www.primaryimmune.org
**Spotlight on Primary Immunodeficiency IDF Family Retreats**

For ten years, IDF Family Retreats have offered members of the primary immunodeficiency community weekends of discovery, learning and fun. And the 2008 Retreats promise more of the same! Two fabulous locations, Gold Canyon Golf Resort in Gold Canyon, Arizona and Hueston Woods Resort and Conference Center in College Corner, Ohio have been selected and we hope you will treat yourself to a great get-away weekend.

The retreats provide an opportunity for people living with primary immunodeficiency diseases to create relationships with others who share common therapies, experiences and feelings. This is a time for all family members — parents, siblings, children and partners — all those who play a role in the patient’s life, develop better coping strategies while learning about treatment and management of these deficiencies.

Leading immunologists will present the latest on medical practices and lead question and answer discussions. Life management and everyday concerns will be featured in panel discussions. There are age-appropriate learning activities for everyone, and of course, there will be fun. By participating in recreational activities, families spend time together and get to know others in similar circumstances.

The IDF Family Retreats are generously sponsored by Baxter Healthcare Corporation, CSL Behring, Grifols, IgG America/ASD Healthcare, Octapharma and Talecris Biotherapeutics.

For more information, call 800.296.4433 or email dgill@primaryimmune.org. Online registration now available at www.primaryimmune.org.

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**IDF CALENDAR OF EVENTS**

**March 25, 2008**
LeBien Visiting Professor — Dr. Luigi Notarangelo
Loyola University Chicago, Maywood, IL
For more information contact Tamara Brown at tbrown@primaryimmune.org

**March 29, 2008**
IDF Operation Outreach Meeting
Albuquerque, NM • 9 am – 2:00 pm
For more information contact Kathy Antilla at kantilla@primaryimmune.org

**April 5, 2008**
Maryland Patient Education Meeting
Columbia, MD
Hilton Columbia • 9:30 am – 2:30 pm
RSVP to Diana Gill at dgill@primaryimmune.org or 410-321-6647 by April 1, 2008

**April 12, 2008**
IDF Family Conference Day
Tulsa Zoo, Tulsa, OK • 9:30 am – 3:00 pm
RSVP to Debbie Kloker at dkloker@cox.net or 918-271-4978

**April 29-30, 2008**
LeBien Visiting Professor Program — Dr. Jennifer Puck
Upstate Medical University, Syracuse, NY
For more information contact Tamara Brown at tbrown@primaryimmune.org

**May 3, 2008**
Promise of Hope Wine Tasting Event
Salvatore’s Restaurant, Lawrence, MA
6:00 pm – 9:00 pm
For information contact Stefani Bush at IDFMA@aol.com or 978-808-6023

**May 3, 2008**
LeBien Visiting Professor Program — Dr. Charlotte Cunningham-Rundles
University of Texas Medical Branch
Galveston, TX
For more information contact Tamara Brown at tbrown@primaryimmune.org

**May 10, 2008**
IDF Patient Meeting, Birmingham, AL
For more information contact Kathy Antilla at kantilla@primaryimmune.org

**May 16, 2008**
LeBien Visiting Professor Program — Dr. Diana Wara
University of California, Davis
Davis, CA
For more information contact Tamara Brown at tbrown@primaryimmune.org

**May 17, 2008**
IDF Patient Meeting
Chicago, IL
For more information contact Kathy Antilla at kantilla@primaryimmune.org

**June 13-15, 2008**
IDF Family Retreats
Gold Canyon Golf Resort
Gold Canyon, AZ

**September 5-7, 2008**
IDF Family Retreats
Hueston Woods Resort and Conference Center
College Corner, OH

**July 16, 2008**
LeBien Visiting Professor Program — Dr. Charlotte Cunningham-Rundles
Cleveland Clinic Foundation, Cleveland, OH
For more information contact Tamara Brown at tbrown@primaryimmune.org

**November 13, 2008**
LeBien Visiting Professor Program — E. Richard Stehm, MD
University of Hawaii at Manoa
Honolulu, Hawaii
For more information contact Tamara Brown at tbrown@primaryimmune.org, or 410-321-6647
Congratulations Travis!

IDF Volunteer Travis Allen from Rigby, Idaho wanted to do something to honor his wife Cajsa and children Taylor and Alessandria who all have primary immunodeficiencies, and help raise funds for IDF. Never one to think small, Travis decided to set his sights on the St. George Marathon in St. George, UT. He had never run a marathon before, so he trained for nearly a year and ran anywhere from five to nineteen miles a day, five days a week. His weekly mileage was usually 25 to 40 miles a week.

“When things got difficult during training and the marathon, I would remind myself that I was running for my family. That really helped me find strength and the determination to get me through the tough times. My goal was to finish the race under four hours, and I was able to finish at 3 hours, 47 minutes.” Travis said. “I learned a great deal about effective ways of raising money and awareness and I plan on making this an annual event.”

When Travis started to ask for people to sponsor his marathon, he cast a wide net. Aside from family and friends, he collected donations from fellow staff members, classmates from his high school reunion, and even employees at the pharmacy where his family gets their prescriptions filled. Travis appeared on the news to explain to the local media what primary immunodeficiency diseases are and why he was running. That brought in even more offerings. His employer, Washington Mutual, Inc., generously also contributed with a corporate match.

Going beyond the distance, Travis, Cajsa and their children also traveled to Great Falls, Montana to the BioLife plasma center to discuss primary immunodeficiency and thank plasma donors for donating their life-saving plasma. Many of the donors appreciated the opportunity to hear the Allen’s story. It “put a face” on the people who benefited from their actions of donating plasma and made their efforts feel even more worthwhile.

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With Gratitude

Travis Allen, his wife Cajsa, their 8 year old daughter Alessandria and 6 year old son Taylor
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