APRIL IS NATIONAL AWARENESS MONTH for Primary Immune Deficiency Diseases

Celebrate Primary Immune Deficiency Diseases Awareness Month this April by educating others about these disorders while advocating for better healthcare legislation. In the United States, more than 50,000 people are diagnosed with primary immune deficiency diseases. Thousands more go undetected. These diseases are chronic illnesses caused by hereditary or genetic defects in the immune system in which part of the body's immune system is missing or does not function properly. These diseases are not contagious.

There are over 120 primary immune deficiency diseases and they affect people differently. For some, the body fails to produce any or enough antibodies to fight infection; while for others, the cellular defenses against infection fail to work properly. Throughout their lives, people with primary immune deficiencies are more susceptible to infections, endure recurrent health problems and often develop serious and debilitating illnesses.

The Immune Deficiency Foundation leads advocacy for healthcare needs, provides medical programs for health professionals, supports research and offers services and educational materials for patients and their families. We need your help to support the primary immune deficiency community—now is the time to take action in your community.

Host a Blue Jeans for Healthy Genes Day

This is a special event when people are asked to make a donation to the IDF for the chance to wear jeans and join the fight against primary immune deficiency diseases. Host this event at workplaces, companies, schools and organizations and seize the opportunity to educate those around you and raise funds for further research and patient programs. Kits with all the materials needed to organize this event and other variations are available from the IDF office or on our Web site, www.primaryimmune.org.

Get the Word Out

Set up a display or post materials at hospitals, health fairs, libraries, plasma centers or other community gathering spots. Contact the IDF office to order free materials and handout information about primary immune deficiency diseases and IDF services.

Contact Your Local Media

Reporters pay attention to stories about real people and now is a great time to share your own personal experience with primary immune deficiency disease. Use this opportunity to educate and spread awareness to the public. Contact your local newspaper and ask about the requirements for submitting an op-ed article or a letter to the editor. Be sure to include contact information for IDF and let others know about the resources that are available through the Foundation. If you need help, sample press releases are available from IDF.

Continued on page 3
We Need Your E-mail Address

Please give IDF your e-mail address by doing one of the following:

E-mail us at idf@primaryimmune.org.

Phone us at 800.296.4433 or 410.321.6647

Register for IDF Action Alert

Please sign up for IDF Action Alert, an online patient advocacy program. With just three clicks, you can reach the registration site.

Go to our Web site www.primaryimmune.org

Click Action Alert on our home page. Click Join Our Supporter List and that will take you to the registration site.

IDF Advocate

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Medical Editor Rebecca H. Buckley, M.D.

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Reach out to your U.S. Senators and Representative in Congress

You do not have to be an expert in government to make your legislators aware of primary immune deficiency disease and its impact on the community. To be an effective advocate, simply tell your own story and share concerns about significant issues, like access to care and IGIV. Personal accounts are essential in putting a real face to primary immune deficiency diseases as well as providing legislators with real examples as to how policy changes can help their voting constituents.

A quick way to find contact information for your legislators is by visiting IDF Action Alert on our Web site, www.primaryimmune.org. By entering your zip code on Action Alert, the names of your Senators and Representative along with a link to their Web sites will appear. Their Web sites will contain their office location, phone number and e-mail address.

Write Your U.S. Senators and Representative in Congress

Ask them to support policy initiatives being pursued by IDF: increasing Medicare and Medicaid reimbursement rates for IGIV therapies, pursuing early diagnosis for primary immune deficiency diseases, developing newborn screening pilot programs for Severe Combined Immune Deficiency and increasing research. Always remember to talk about your own family’s experiences. Create your own letter, or use the drafted letters and talking points on IDF Action Alert, and easily send an e-mail. Alternatively, if you prefer, mail to the legislator’s state or Washington, D.C. office.

Meet with Your Members of Congress in Their Local Offices

The ability to sit down face-to-face with your elected officials remains the most powerful tool that you can utilize to increase awareness about primary immune deficiency diseases. Members of Congress have congressional breaks when they leave Washington, D.C. to spend time in their respective districts and meet with their constituents. They are often in their district offices on Mondays and Fridays, reserving Tuesday through Thursday evenings on Capitol Hill when Congress is in session. Because they represent the total population in their state, it is often difficult for Senators to meet with individual constituents. However, U.S. Representatives routinely set aside time when they are in their district offices to meet with the individuals they represent. We encourage you to seek a meeting with your legislators in their local district offices.

Take Action

Primary Immune Deficiency Disease Awareness Month is the perfect time to undertake some of these ideas or try a few of your own. IDF staff is available to answer questions, help with plans and provide the materials you need. Educational, advocacy, fundraising or promotional materials are all free of charge.

Contact IDF by calling 800.296.4433 or e-mailing idf@primaryimmune.org.

MAKE AN APPOINTMENT WITH YOUR LEGISLATORS

1. Find contact information for your official

Find contact information for your legislators by visiting IDF Action Alert on our Web site, www.primaryimmune.org, or check the phone book or library.

2. Call the district office and speak with the scheduler

• Identify yourself as a constituent
• Tell the scheduler that you would like to meet with your legislator in the district office
• State that the reason for your visit is to discuss primary immune deficiency diseases
• Agree upon a mutually convenient date and time
• Confirm names of anyone else who will be coming with you

3. Contact IDF for materials for your legislator visit

Call IDF to obtain a folder with all the information needed for your visit. The packet has information on primary immune deficiency diseases, healthcare legislation and IDF. Included is a “leave behind” handout for you to give to the official and a sample thank-you letter you could use.

4. During the Meeting

• Begin by thanking the Member for his or her time
• Introduce yourself as a constituent and give the name of your hometown
• Tell about your connection to primary immune deficiency diseases and share your family’s personal experience
• Highlight facts about primary immune deficiency diseases; this information will be included in the folder of visit materials
• Present the “leave behind” handout
• Urge the legislator to support IDF’s policy initiatives
• Tell them of any upcoming IDF events in your area
• Thank them again for allowing you to share your thoughts and concerns

5. Follow Up Your Visit With a Thank-You Letter

Follow up the meeting with a thank you letter that highlights the topics you discussed in your meeting; a sample thank-you letter is included in the folder of visit materials.
A study published in January 2006 in the online edition of *Clinical Immunology* reveals that adults diagnosed with X-linked agammaglobulinemia (XLA) lead productive lives, despite vulnerability to chronic, low-grade infections. According to Mary Ellen Conley, M.D., senior author of the study and member of IDF’s Medical Advisory Committee, “We and other physicians were quite surprised at how well these patients are doing with proper care.”

XLA is characterized by profound hypogammaglobulinemia and markedly decreased or absent B-cells. The disease was first described by Colonel Ogden Bruton in 1952 and in 1993 it was demonstrated that XLA was caused by a mutation in the Btk gene (for Bruton tyrosine kinase) on the X-chromosome. Until the 1980s, most affected patients died at less than twenty years of age. However, because of improvements in diagnosis and therapy in the past two decades, most patients are doing well in adulthood.

**Study Population**

Researchers at St. Jude Children’s Research Hospital identified 69 adult males with a definitive diagnosis of XLA as potential subjects for the study. Fifty-three patients agreed to participate and 41 ultimately returned the survey and answered questions about treatment, general health, medical problems, cost of medical care and quality of life. These individuals had a mean age of 4 years when their disease was diagnosed and 58% had a family history of XLA. When compared to all XLA patients, a high percentage of the respondents had mild mutations in Btk and most had older brothers or cousins with XLA. Therefore, they may have been diagnosed earlier and treated more aggressively.

**Treatment**

All but one of the patients received intravenous immune globulin therapy every two to four weeks. Thirty-nine percent of patients were taking chronic prophylactic antibiotics and 54% had taken chronic antibiotics for at least two years in the past. Five patients reported using alternative therapies including oral colostrum, stress reduction techniques and herbal medicines.

**General Health**

The majority of patients had not experienced major health problems. Forty-one percent had not been hospitalized since diagnosis and 68% had not been hospitalized in the last five years. Eighty-five percent of the patients were working full time or were full time students. Eighty-six percent of patients missed fewer than 10 days of work or school due to illness in the past year and 44% reported they had not missed any work or school. Sixty-one percent of the patients reported being involved with sports as children or adolescents and 34% said they were currently involved in sports.

**Medical Problems**

Chronic lung disease was the most frequently reported major medical problem. Nine patients reported chronic lung disease and four more reported permanent loss of lung function due to XLA. Three fourths of the patients diagnosed after age 18 reported lung disease, suggesting delayed diagnosis may result in lung disease.

Infections of the upper respiratory tract were commonly reported. Seventy-one percent of the patients without chronic lung disease reported at least one episode of sinusitis and 61% reported cough and bronchitis. Diarrhea, conjunctivitis, otitis media (ear infection), arthritis and skin infections were also seen in a notable number of patients. Interestingly, hypertension and type II diabetes, commonly seen in adults, were rarely reported.

**Cost of Medical Care**

While 40 of the 41 patients indicated they had health insurance, nearly half of the subjects reported some difficulty in obtaining or maintaining health insurance. Thirty-four percent of patients reported that at some time they did not get appropriate care, including prescriptions, immune globulin therapy, access to a specialist and operations, because of the cost.

**Quality of Life**

While some patients reported that XLA affected their lifestyle and career choices, their quality of life was equivalent to the general male population in the United States and better than patients with diabetes.

**Improved Outlook**

The study’s first author, Vanessa Howard, RN, MSN, summarized, “Almost all of the adults with XLA had chronic medical problems; however, these problems did not interfere with normal daily activities, and the quality of life in this group was equivalent to that of the general male population in the United States...in the last twenty years the outlook for patients with XLA has significantly improved, thanks to earlier diagnosis and improved gamma globulin therapy. Our study is reassuring and helps to put in perspective the ability of patients to thrive with proper care, despite this potentially devastating disease.”

**Authors of the study:** Vanessa Howard R.N., M.S.N.1, Jeffrey M. Greene M.D.2, Savita Pahwa M.D.3, Jerry A. Winkelstein, M.D.4, John M. Boyle, Ph.D.5, Mehmet Kocak M.S.6, Mary Ellen Conley M.D.1,7

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1 Department of Immunology, St. Jude Children’s Research Hospital, Memphis, TN
2 Department of Pediatrics, Children's Hospital of Philadelphia, Philadelphia, PA (deceased)
3 Department of Microbiology and Immunology, University of Miami School of Medicine, Miami, FL
4 Department of Pediatrics, The Johns Hopkins University School of Medicine, Baltimore, MD
5 SRBI, Silver Spring, MD
6 Department of Biostatistics, St. Jude Children’s Research Hospital, Memphis, TN
7 Department of Pediatrics, University of Tennessee College of Medicine, Memphis, TN
NEW IDF CLINICAL GUIDELINES NOW AVAILABLE

The Immune Deficiency Foundation Diagnostic and Clinical Care Guidelines for the Primary Immunodeficiency Diseases, the first comprehensive guidelines on these diseases, is now available. In partnership with expert immunologists, IDF developed these guidelines to enhance earlier diagnosis, improve health outcomes and increase access to specialized health care and optimal treatment for patients with primary immunodeficiency diseases. The guidelines include recommendations, strategies and information that will assist physicians and patients in making educated decisions about appropriate health care for the primary immunodeficiencies. The development of the guidelines was funded by an educational grant from Talecris Biotherapeutics.

For a copy, visit www.primaryimmune.org or call IDF at 800-296-4433.

IDF Medical Advisory Committee 2006

The Immune Deficiency Foundation’s Medical Advisory Committee supports the mission of the IDF through the development of science-based standards for diagnosis and care for individuals with primary immune deficiency diseases and their complications. They promote key research issues that increase understanding of the pathogenesis and potential cure of primary immune deficiency diseases.

The committee is comprised of a prominent group of physicians and scientists, each having advanced the diagnosis, treatment and/or immunologic understanding of primary immune deficiency diseases. Members represent the IDF at scientific and policy events, participate in the Consulting Immunologist and Visiting Professor Programs, and are involved in program development and special projects.
REDUCED REIMBURSEMENT IMPACT ON PATIENT CARE

The Immune Deficiency Foundation (IDF) was founded with the conviction that people with primary immune deficiency diseases deserve better health and a strong organization that would advocate for them. Listening to the primary immune deficiency community and responding to their needs is paramount to the mission of IDF. Therefore, it is with growing concern that since January 1, 2005, our office has been flooded with calls from patients whose care has been adversely affected by reductions in Medicare reimbursement for immune globulin intravenous therapy (IGIV). We are hearing first hand how this threatens our community and patients’ ability to receive IGIV treatment.

As of January 1, 2006, the Centers for Medicare and Medicaid Services (CMS) new ruling for IGIV reimbursement formula went into effect for all sites of care for Medicare patients, with hospitals being reimbursed under the same formula as physician offices and home care settings. This ruling reduced the rates of reimbursement for IGIV at hospitals and as we feared, some hospitals became overburdened with too many patients who once received their IGIV from homecare settings or physician offices. Consequently, some hospitals have turned away patients seeking IGIV. This has resulted in patients losing the only site of care that was available to them. IDF is monitoring these situations closely, reporting the cases to leaders at the Department of Health and Human Services and intervening when possible.

Unfortunately, these reports are no surprise. Since January 2005 when Medicare dramatically reduced reimbursement rates of IGIV in physician offices, outpatient infusion suites and home care settings, calls from patients and physicians describing problems getting IGIV have been on the increase.

**IDF Surveys**

To further explore the effects of the reduced Medicare reimbursement rates, IDF commissioned a national survey titled, “Intravenous Immunoglobulin Availability and Access among Medicare Patients with Primary Immune Deficiency Diseases.” The telephone survey was conducted between May and July 2005 among patients with primary immune deficiency diseases who had reported Medicare coverage in two previous national patient surveys. Schulman, Ronca and Bucuvales, Inc., an international research organization, conducted the survey.

**The troubling findings included:**

Thirty-nine percent of patients reported IGIV problems, which included:

- 16% postponed infusions
- 12% changed locations for infusions
- 11% increased intervals between infusions
- 6% received a lower dosage
- 4% switched to a less tolerated product
- Of the 12% who changed site of infusion, 51% reported receiving their infusions in a doctor’s office a year ago, as opposed to 9% at the time of the survey.

These problems resulted in negative health outcomes in 40% of the patients who reported experiencing problems. Fifty-five percent of those who had experienced problems were not confident in their future ability to obtain appropriate treatment.

Concurrently, IDF commissioned a separate national survey among 286 physicians who treat patients with a primary immune deficiency disease using IGIV, totaling 4189 patients. The results of this survey correlated closely with the patient survey with physicians identifying similar problems of their patients.

Thirty-nine percent of physicians reported patients experiencing significant problems related to reduced reimbursement of IGIV. Of this group, 43% reported adverse health effects on patients as a result of the reduction. The impact on patients included:

- 22% postponed infusions
- 21% switched to a different site of care,
- 8% had the interval between infusions increased
- 13% switched brands

The information gathered from these new IDF surveys represented the only quantifiable data that demonstrated to Members of Congress, the CMS and other government agencies that the Medicare reimbursement reductions had a negative impact on patient care.

Now, with the arrival of 2006, the difference in reimbursement that had favored hospitals over the past is no longer in effect. Because of our advocacy efforts last year, CMS did offer a pre-administration fee for IGIV in 2006 only. However, this is not enough to solve the problems that have been created for our patients. Reductions in Medicare IGIV reimbursement rates have resulted in treatment problems, negative health outcomes and low confidence in future treatment among patients with primary immune deficiency diseases.

IDF will continue to fight for healthcare reform to support our community. Please alert us to any problems you experience and let us know your e-mail contact information, as we may need to contact groups quickly. IDF appreciates your dedication and involvement to help us achieve our mission.
2006 MEDICARE REIMBURSEMENT RATES FOR IGIV FIRST QUARTER

Hospital Outpatient Setting
Reimbursement for hospitals has been reduced from $80.68 per gram for all brands of IGIV to $44.44 per gram for lyophilized brands and $56.72 per gram for liquid brands. Hospitals may also bill a $75 pre-administration fee per infusion in 2006 only.

Physician Offices, Infusion Centers and Home Care Settings
Reimbursement will continue under the same formula as in 2005. The current rate is $44.44 per gram for lyophilized brands and $56.72 per gram for liquid brands. Providers may bill a $69 pre-administration fee per infusion in 2006 only.

There is much confusion about Medicare coverage for patients with primary immune deficiency diseases. While IDF is still researching the new program and monitoring the implementation, we want to inform the community that IGIV is not covered under Part D for primary immune deficiency diseases. The Medicare Modernization Act included a special provision under Medicare Part B that covers IGIV for primary immune deficiency diseases in the home care setting. Therefore, if a patient is covered by Medicare, selecting the option of Part B is necessary for proper reimbursement of many of the therapies for primary immune deficiency diseases. Additionally, since coverage of these therapies is usually limited to 80%, it is also important that a patient considers selecting a Medigap policy to help defray the cost of the 20% for which the patient is typically responsible.

The new Part D coverage that became available in 2006 includes prescription drugs that were not previously covered under Medicare. Since IGIV is covered for primary immune deficiency diseases in the home care setting under Part B, only patients who do not have primary immune deficiency diseases may be eligible for coverage under Part D. If you are a primary immune deficiency patient, your IGIV is not covered under Part D. Please be cautious when speaking with people who tell you otherwise. Contact IDF with any questions or concerns you may have.

Question: What is an infusion log and why should I keep one?

Answer:
An infusion log is simply a personal record of your immune globulin infusions. Seventy percent of people with primary immune deficiency diseases administer immune globulin either intravenously or subcutaneously and keeping an infusion log is a good way to keep track of infusion activity. There are five basic parts to record:

1. The brand of immune globulin
2. The date of infusion
3. The lot of the immune globulin
4. The amount of immune globulin
5. Any side effects or adverse events experienced

There are real benefits to keeping track of which brand of immune globulin you receive, and how often you receive it. Sometimes, patients may tolerate one manufacturer’s immune globulin product better than another and knowing which brand you have allows you and your doctor to determine which brand is best for you. Also, in some instances you may need to receive your dose of immune globulin a few days early or late, and recording the date allows you to maintain a relatively regular schedule. In other cases, you may need to switch physicians and/or infusion sites or services, and the log can provide valuable information to allow consistent infusions.

On rare occasions, a problem is identified in a specific lot of immune globulin from a specific manufacturer. With good record keeping, you can know if the potential problem affects you or you can avoid infusing the specific lot. The best way to learn about these types of problems when they happen is to sign up for the Patient Notification System, by calling 1-888-UPDATEU (1-888-873-2838). This service provided at no cost, is a confidential, 24-hour communication system providing information on IGIV therapy withdrawals and recalls via e-mail, telephone or fax.

Free copies of the IDF publication “How to Keep an Infusion Log” with information on the Patient Notification System are available from IDF at idf@primaryimmune.org or 800.296.4433.
Baxter to Discontinue Production of IVEEGAM EN beginning January 1, 2007

IVEEGAM EN [Immune Globulin Intravenous (Human)] [IVIG] will no longer be available beginning January 1, 2007. This decision is a direct reflection of the optimization of Baxter’s manufacturing processes, which has led to improvement in the efficiency of production and thus availability of the IVIG products offered by Baxter. Usage of IVEEGAM EN constitutes less than 0.3% of the total amount of IVIG used in the United States, therefore, given our ability to supply alternative therapies, we will ensure that the withdrawal of IVEEGAM will not significantly impact the availability of IVIG. We have made a decision to focus on our next generation IVIG therapies, and thus it will be necessary to transition patients from IVEEGAM EN.

Excerpted from Baxter Dear Doctor Letter January 5, 2006

ZLB Behring Announces FDA Approval Of Vivaglobin® -- The First Subcutaneous Immunoglobulin Replacement Therapy Approved in the U.S.

ZLB Behring announced that the U.S. Food and Drug Administration (FDA) has granted marketing approval for Vivaglobin® (Immune Globulin Subcutaneous [Human]), an immunoglobulin (Ig) replacement therapy for treating patients with primary immunodeficiency (PI). Vivaglobin is the first and only FDA-approved subcutaneous (SC) Ig treatment, and can be safely self-administered by PI patients under a physician’s care in the United States. Vivaglobin is manufactured and marketed by ZLB Behring.

Vivaglobin delivers treatment directly under the skin (subcutaneously), offering a safe and effective alternative to intravenous infusions of immunoglobulin. Vivaglobin represents another treatment option for patients who may not easily tolerate the currently available intravenous method because they have poor venous access or experience serious side effects from that method. Vivaglobin also is appropriate for those who want the freedom and convenience of safe home self-administration of Ig replacement therapy.

Excerpted from ZLB Behring News Release, January 9, 2006

Varicella Zoster Immune Globulin (VZIG) – Anticipated Short Supply and Alternate Product Availability under an Investigational New Drug Application Expanded Access Protocol

The only manufacturer of U.S.-licensed VZIG, Massachusetts Public Health Biologic Laboratories (Boston, MA), has discontinued production of this product, which is indicated for patients in need of passive immunization to prevent severe varicella zoster infection. The supply of the licensed VZIG product is nearly depleted. However, an investigational (not licensed) VZIG product (manufactured and currently under development by Cangene Corporation Winnipeg, Canada) is available under an investigational new drug application (IND) protocol. This product may be requested through FFF Enterprises (Temecula, CA) for individuals who have been exposed to varicella and who are at increased risk of complications from varicella.

The investigational VZIG, like licensed VZIG, is a purified human immune globulin preparation made from high anti-varicella antibody-containing plasma. The investigational product is lyophilized. When properly reconstituted, it is a 5% solution of IgG, which is intended to be administered intramuscularly. As with any product used under IND, patients must be informed of potential risks and benefits and give informed consent before receiving the product.

If a decision is made to use VZIG, it should be administered as soon as possible after exposure, and within 96 hours of exposure.

Excerpted from FDA Web site posting 2/8/06. For more information and to find out patient eligibility, visit: http://www.fda.gov/bbs/topics/NEWS/2005/NEW01266.html

ANNUAL IDF SCHOLARSHIP PROGRAM

For twenty years, the Immune Deficiency Foundation (IDF) has awarded scholarships to undergraduate students living with primary immune deficiency diseases. IDF is honored to assist students who have managed the challenges of living with these chronic illnesses and are pursuing their secondary education.

IDF Scholarship Program is open to students with a primary immune deficiency disease as classified by the World Health Organization. The scholarships are intended for undergraduate students attending or entering college or a technical training school.

The deadline for applications is March 31, 2006. Interested applicants can obtain an application on our Web site www.primaryimmune.org or by contacting Tamara Brown at 800.296.4433.

SAFETY INFORMATION

FDA Approves First Test to Screen for West Nile Virus in Donors of Blood, Organs, Cells and Tissues

FDA today announced the approval of the first West Nile Virus (WNV) blood test to screen donors of blood, organs, cells and tissues. The Procleix WNV Assay, developed by Gen-Probe Inc., and marketed by Chiron Corporation, detects viral genetic material (ribonucleic acid or RNA). This new test will help protect patients who receive blood and other such products against West Nile infection. To date, there have been 30 documented cases of people who most likely acquired WNV from a blood transfusion, including nine who died.

West Nile Virus is typically transmitted to humans by mosquito bites. It was first detected in the United States in 1999, and has reoccurred each year for seven consecutive years, causing close to 20,000 human cases of disease and at least 762 deaths since 2002. It is estimated that between 1 and 2 million people have been infected with WNV.

In 2002, it was discovered that WNV could be transmitted in blood and an urgent effort to develop a blood test began. With support from FDA, the Centers for Disease Control and Prevention and the National Institutes of Health, manufacturers developed investigational WNV tests that were rapidly put in place both to evaluate their effectiveness and as an interim measure to protect the blood supply. Blood banks across the United States participated in these efforts, resulting in the detection and removal of approximately 1,600 infected donations, safeguarding the blood supply and providing the needed data for today's approval.

Excerpted from FDA News Release, December 1, 2005. For more information, visit: http://www.fda.gov/bbs/topics/NEWS/2005/NEW01266.html

Varicella Zoster Immune Globulin (VZIG) – Anticipated Short Supply and Alternate Product Availability under an Investigational New Drug Application Expanded Access Protocol

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If a decision is made to use VZIG, it should be administered as soon as possible after exposure, and within 96 hours of exposure.

Excerpted from FDA Web site posting 2/8/06. For more information and to find out patient eligibility, visit: www.fda.gov/cber/infosheets/mphvzig020806.htm
WELCOME
DR. BLAEE

The Immune Deficiency Foundation (IDF) is proud to announce that R. Michael Blaese, M.D. will be joining the organization as the Medical Director of IDF. He will administer the US Immunodeficiency Network (USIDNET) and be involved in many other IDF projects.

During all four years of medical school at the University of Minnesota School of Medicine, Dr. Blaese worked in the laboratory of Professor Robert A. Good who is widely regarded as the “Father of Clinical Immunology.” This experience set the direction for Dr. Blaese's life-long interest and dedication to the study and treatment of the primary immunodeficiency diseases.

Dr. Blaese became a member of the faculty of the National Institutes of Health and for the next 33 years, his work spanned a broad range of areas from basic research in immunology, virology, cancer, and molecular genetics to clinical care and investigation of the primary immunodeficiency diseases and the development of innovative new therapies. In 1984, Dr. Blaese and French Anderson joined forces to develop the use of genes as medicines, a pioneering collaboration that led to the first successful human gene therapy in 1990 for a 4-year-old girl with ADA deficiency SCID. As Chief of Clinical Gene Therapy for the Human Genome Institute, he continued to lead the early development of gene therapy introducing clinical trials for inherited immunodeficiency, brain cancer and AIDS. In 1999, he moved to the biotech industry where he has spent the past seven years working to develop treatments for orphan genetic diseases. Most recently, Dr. Blaese has served as Medical/Research Director of the Institute for Inherited Disease Research. He also is the Founder and President of PreGentis, a biotech company working to develop a new approach to gene therapy for inherited diseases that he hopes will be more effective than traditional gene transfer technology for treating many of the primary immunodeficiency diseases.

Dr. Blaese has been a member of the IDF Medical Advisory Committee of IDF since 1987 and in 2000, he received the Boyle Achievement Award for his work with primary immunodeficiency diseases. He is excited about joining the staff of the IDF and working to assist in programs toward improving the lives of patients with primary immunodeficiency.

USIDNET RESEARCH AWARDS TOP $5 MILLION

The US Immunodeficiency Network (USIDNET) is an international consortium established to advance scientific research in the primary immune deficiency diseases. All research funded through USIDNET is dedicated to issues of primary immune deficiency diseases and is peer reviewed. Since 2003, the consortium has approved eighteen research proposals for funding totaling five million dollars.

The following are recipients of funding through USIDNET:

November 2005
Anna M. Blom, Ph.D.
Lund University – Malmö, Sweden
Scott B. Snapper, MD, Ph.D.
Massachusetts General Hospital

July 2005
David T. Teachey, MD
The Children’s Hospital of Philadelphia

March 2005
Emanuela Castigl, Ph.D.
Children’s Hospital, Boston
Douglas McDonald, MD, Ph.D.
Children’s Hospital, Boston
Janos Szumb, MD, Ph.D.
Cincinnati Children’s Hospital Medical Center
Bodo Grimbacher, MD
University of Freiburg, School of Medicine

November 2004
Carol Miao, Ph.D.
Children’s Hospital and Regional Medical Center, Seattle, Washington
Yatin Vyas, MD
Children’s Hospital of Pittsburgh

July 2004
Anthony Infante, MD, Ph.D.
University of Texas Health Science Center
Jordan Orange, MD, Ph.D.
The Children’s Hospital of Philadelphia

Carol Webb, Ph.D.
Oklahoma Medical Research Foundation

March 2004
Ramsay Fuleihan, MD
Yale University School of Medicine
Donald Kahn, MD
Children’s Hospital Los Angeles
Narayanaswamy Ramesh, Ph.D.
Children’s Hospital, Boston

January 2004
Andrew Scharenberg, MD
University of Washington
Charlotte Cunningham-Rundies, MD, Ph.D.
Mt. Sinai School of Medicine, New York
Kim Nichols, MD
The Children’s Hospital of Philadelphia

You say IVIG, I say IGIV: What is the Difference?

Intravenous immune globulin therapy is gamma globulin (the protein fraction of blood that contains immune globulins or antibodies) therapy that is injected directly into a vein. The term is quite a mouthful and is often abbreviated to IGIV or IVIG. Both terms refer to the same thing and can be used interchangeably. Typically, IGIV is usually used in medical settings, by the Food and Drug Administration and on product inserts, while IVIG is commonly used by industry trade organizations and government organizations such as the Centers for Medicare and Medicaid Services.

USIDNET is funded by the National Institute of Allergy and Infectious Diseases and the National Institute of Child Health and Human Development, which are components of the National Institutes of Health, an agency of the Department of Health and Human Services.
Operation Outreach are programs for patients, families and health professionals that are held throughout the U.S. These one-day meetings offer educational sessions, peer support activities and networking opportunities. The meetings often feature leading clinical immunologists addressing treatment and management of primary immune deficiency diseases, insurance reimbursement specialists offering advice and resources and policy experts discussing legislative issues affecting the primary immune deficiency community. ZLB Behring sponsors Operation Outreach. Registration required, contact Diana Gill at 800.296.4433.

**March 18**  
Operation Outreach -- Philadelphia, PA  
*Franklin Institute Science Museum*  
Speakers: Jordan Orange, MD, PhD and Kathleen Sullivan, MD, PhD

**April 8**  
Operation Outreach -- Little Rock, AR  
*Statehouse Convention Center*  
Speakers: Terry Harville, MD, PhD; Stacie Jones, MD; Tamara Perry MD and Amy Scurlock, MD

**April 28-30**  
IDF Volunteer Leadership Conference  
*Los Angeles, CA*

**June 9-11**  
IDF Family Retreat  
*Wintergreen Resort  Wintergreen, VA*

The LeBien Visiting Professor Program fosters improved knowledge about the diagnosis and treatment of primary immunodeficiency diseases. The program provides expert clinical immunologists to lead grand rounds and other educational activities at teaching hospitals throughout North America. For more information, contact Tamara Brown at 800.296.4433.

**July 15-17**  
LeBien Visiting Professor Program with Dr. Charlotte Cunningham-Rundles  
*California Society of AAI, Huntington Beach, CA*

**November 15**  
LeBien Visiting Professor Program with Dr. Hans Ochs  
*Children’s Medical Center at Dallas, Dallas, TX*

**Registration begins January 2007**

Visit our Web site for updates  
Scott Franks, son of Katie and Paul Franks of Lakewood, Ohio, doesn’t let his primary immune deficiency stop him from his work supporting IDF. Scott, age 18, organized a blood drive at the civic center in Rocky River, Ohio that also served as a fundraiser. Not only did the event raise $3,875, but it also encouraged 108 people to donate blood and 85% were first time donors. A local company was so impressed with Scott’s efforts and success that they plan to sponsor another blood drive in honor of Scott this March.

When Landon Levine was diagnosed with primary immune deficiency disease a little over a year ago, his parents, Liza and Larry, made a commitment to help raise money for IDF. Both being marathon runners, they approached friends, family and associates to sponsor their runs and the response was overwhelmingly generous. Their sponsors sympathized with the Levine’s life-long situation and were grateful that they could help in any way. Larry ran the Disney marathon last year and raised about $7,000 and Lisa’s run in the Palm Beach marathon this year, brought in around $2,000. Lisa feels that, “Each step takes us closer to finding a cure. Landon is only three years old and is not aware of the purpose for our runs, but we are committing to this once a year or until there is a cure for Landon!”

Evelyn C. Maselli and Terri Lowell, organized “A Night of Laughter” Comedy Show to benefit the IDF on November 4, 2005 in West Haven, Connecticut. Terri and Evelyn, longtime IDF supporters, are currently planning, “Wines of the World,” a wine tasting event with fabulous cuisine, live and silent auction, exceptional music and inspirational moments, on April 7 at the Savin Rock Conference Center in West Haven. For more information, visit: www.winesoftheworldinct.com
NEW IDF ACTION ALERT--

Restore Access to IGIV in All Sites of Care for Medicare Recipients

Visit our Web site, www.primaryimmune.org, and click on IDF Action Alert to personally send out the new alert to Congress.