IDF Presents Survey Results
Successful Symposium at AAAAI Conference

Long the national source for reliable data, IDF has a wealth of unique information about the real experiences of the primary immunodeficient community. Highlights from five IDF surveys conducted over the last decade were presented at the IDF Symposium on Prevalence, Patient Characteristics and Treatment Patterns in Primary Immune Deficiency Diseases (PIDD) held at the American Academy of Allergy and Immunology (AAAAI) Annual Meeting on Friday, February 23, 2007 in San Diego. Marcia Boyle, President & Founder of IDF, welcomed approximately 150 immunologists, medical professionals and other guests from all over the world. The panel of presenters included John Boyle, PhD, Rebecca Buckley, MD, Vivian P. Hernandez-Trujillo, MD and Jordan Orange, MD, PhD.

Dr. John Boyle began by presenting the overview of the results of IDF surveys conducted over the past decade. He demonstrated how these survey results have established a clear picture of the complicated world of primary immunodeficiency. Treatment experiences, health status, IVIG use and challenges that faced, and continue to face, the entire PIDD community were all addressed.

Dr. Jordan Orange and Dr. Boyle presented the results of the 2006 Patient, Physician and Hospital Pharmacist Surveys on IVIG Reimbursement and Availability. Patients with PIDD are finding it more difficult to obtain their IVIG therapy either in sufficient dosages or in a timely manner. Additionally, fewer doctors are infusing PIDD patients in their offices and as a result, more PIDD patients must obtain their infusions from hospitals. Survey results showed increased infections, pneumonia, bronchitis, and antibiotics use among those who have had difficulty obtaining their IVIG. Although those on Medicare are much more likely to experience these types of problems, individuals who have private pay insurance are beginning to see challenges in obtaining their IVIG therapy as well. The reason for this situation is quite clear. Almost half of the physicians (44%) and almost a third (30%) of the hospital pharmacists reported that they paid more for liquid IVIG than they were reimbursed. Eighty-one percent (81%) of the physicians and 57% of the pharmacists reported paying more for lyophilized IVIG than they were reimbursed.

continued on pg.2.
Register for IDF Action Alert

Sign up for IDF Action Alert, our online patient advocacy program that makes it easy for all individuals to impact legislation. It is a simple and effective way for people to voice their issues and directly influence the political progress.

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

IDF Advocate

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The Immune Deficiency Foundation publishes IDF Advocate three times a year. To obtain a free subscription, please contact:
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“IDF Presents Survey Results ...”, cont’d.

In regards to the physician survey findings, Dr. Orange commented, “current reimbursement standards represent a significant risk to the health of patients with primary immunodeficiency diseases. Patients are being forced to change optimal treatment location, infusion intervals and/or dosing amount, in some case foregoing treatment for extended periods. As a result, some of these vulnerable patients have experienced additional or more severe health effects.”

Dr. Rebecca Buckley presented the results of the IDF Survey of the Prevalence of Primary Immune Deficiency. A national probability sample of 10,000 households was sampled by telephone to identify how many of the nearly 27,000 household members had been diagnosed with a primary immunodeficiency disease. Based on the data, Dr. Buckley believes, “immune deficiency diseases are far more common than previously thought.” Details of this groundbreaking survey will be released as soon as the report is finalized.

Dr. Orange discussed results from the IDF/AAAAI/ESID specialist surveys. Some of the findings suggested that specialists in primary immunodeficiency diseases prescribe more aggressive therapies than those who did not specialize in PIDD. According to the survey, there are important differences between and among immunologists in how they choose to treat PIDD patients. There are also significant differences between how American and European physicians treat their PIDD patients.

Dr. Vivian P. Hernandez-Trujillo briefed the audience on an exciting upcoming IDF survey of pediatricians. This survey will be administered through the American Academy of Pediatrics membership to understand the perceptions of and practices by generalists as applied to patients with PIDD. The survey aims to contrast the differences, if any, between generalist and specialist treatment of PIDD. The survey results will be used as educational points of focus to aid in improving the early diagnosis of these patients.

The IDF would like to thank all of those in our community who participated in these surveys, for without their time and effort, these groundbreaking, important surveys would not have been possible.

This symposium was made possible by an educational grant from Talecris Biotherapeutics. For additional information about this symposium or other IDF survey findings, please contact Christopher Scalchunes, Director of Survey Research, at cscalchunes@primaryimmune.org or 800-296-4433.
As the leader and voice of primary immunodeficient patients, the Immune Deficiency Foundation (IDF) knows our patients can’t wait any longer. Since January 2005, IDF has been working to establish a permanent and comprehensive solution to patient access to immunoglobulin therapy (IVIG). We know that reductions in Medicare reimbursement rates have resulted in patients being turned away from their own doctors’ offices for treatment, and suffering negative health outcomes because they have had to postpone treatments or increase the time between treatments.

So we took action. We placed the advertorial, “Bureaucracy to Die For...”, in Roll Call, the newspaper of Capitol Hill and the leading publication for Congressional news and information. We wanted to gain the attention of Congress and press for the release of two reports—one by the Office of Inspector General and another requested by the Secretary of Health and Human Services, which members of Congress have requested before they will act. Time is running out for our patients who have no other treatment available to them except IVIG.

Congress must act now to fix the Medicare reimbursement problem for IVIG.

It is our duty to represent patients with primary immunodeficiency diseases. IDF will continue to fight for healthcare reform to support our community. Currently, new legislation is being drafted and IDF is on the forefront to ensure that action is taken.

To view the complete advertorial, go to www.primaryimmune.org. While on our Web site, we urge you to continue to send your stories and messages to Congress through IDF Action Alert.

“Bureaucracy to Die For...”

Breaking Good News!
New Codes for Immune Globulin Products

On April 18, 2007, the Centers for Medicare Services (CMS) announced it will recognize separate codes for each intravenous immune globulin (IVIG) product. In the long-term, separate codes for each IVIG product will help individuals with primary immunodeficiency diseases because they will provide more accurate pricing data for each immunoglobulin product. IVIG products are unique products and, by definition, are not bioequivalent. Although patients and their physicians may decide to switch products, the potential for side effects should not be taken lightly. Patients should not be forced to switch products solely due to cost.

Although separate IVIG codes do not fix the overall Medicare reimbursement problem, the codes should serve to make all products available to patients on Medicare. This is because the calculation to determine Medicare payment will be based only on the sales price for that product and not group together all IVIG products regardless of patient need, preference and/or product cost.

This recognition of separate codes for immune globulin products by CMS is the result of the advocacy of IDF and many others. By tirelessly advocating for patients with primary immunodeficiency diseases and working with other organizations and stakeholders, we have helped to persuade CMS to reevaluate how they have looked at IVIG. This is a major change and will hopefully lead to an adjustment in the way CMS pays for IVIG to assure access to care.

We sincerely appreciate all of you who have contacted your Members of Congress and shared your concerns. It has truly made a difference! However, it is not a time to become complacent. Please keep it up and maintain your advocacy efforts along with IDF as we continue to fight to restore access to IVIG in all sites of care.
Q&A With Representative Jim McCrery

For several years, IDF has worked closely with Congressman Jim McCrery of Louisiana. Mr. McCrery is an influential member of the U.S. Congress, having served our country for the past twenty years. He is the Ranking Republican Member of the powerful House Committee on Ways and Means which has jurisdiction over tax, trade and Medicare policy. Mr. McCrery is recognized as one of the most thoughtful members of the United States Congress, focusing on solving America’s challenges by looking past politics of the moment and toward long-term, permanent solutions. He will be personally involved in any legislation impacting Medicare payment for IVIG. Recently, IDF talked to Mr. McCrery about issues of importance to individuals with primary immunodeficiency diseases.

Congressman McCrery, are you aware of the problems many Medicare beneficiaries are facing regarding IVIG?

Yes, in fact, many of my colleagues and I have heard directly from our constituents regarding their unfortunate experiences trying to locate providers who will infuse Medicare beneficiaries. My staff is in regular communication with IDF and has worked with them to better quantify the problem.

You are the Ranking Republican of the House Committee on Ways and Means with jurisdiction over the Medicare program. What do you expect your committee will do regarding Medicare reimbursement of IVIG?

It is very important that Congress have independent data to fully understand why patients are experiencing difficulties. Without it, we don’t know if we are truly addressing the underlying problem. Currently, Congress is awaiting the results of two studies focused on IVIG availability and reimbursement. The Committee has been briefed on parts of the reports and it is my hope the completed reports will be released soon. Congress has been waiting for a long time for the government-sponsored studies to be completed and made public.

To encourage completion of the studies, I worked closely with my colleagues and the immune deficiency community to include a statement in the Tax Relief and Health Care Act of 2006. Specifically, we expressed our hope that the Secretary of Health and Human Services will “promptly review such studies, and report to the House regarding the adequacy of supply and Medicare reimbursement related to the cost of acquiring IVIG and the complexity of IVIG infusions.” Also, I sent a letter to the Secretary urging the timely completion of these studies.

What is Medicare currently doing to stabilize the IVIG access issue?

This past fall, the Centers for Medicare and Medicaid Services (CMS) had proposed eliminating a pre-administration fee paid to physicians to assist in acquiring IVIG. After many public comments opposed to this provision, CMS determined they would continue the pre-administration fee. I worked with my colleagues in the House of Representatives to include a statement urging the Secretary of Health and Human Services “to continue the IVIG pre-administration fee until the Secretary either assures the House that Medicare reimbursement is adequate or a new payment methodology is implemented to address concerns regarding access to IVIG.”

The independent data gathered from the studies Congress is awaiting should help to answer the question of whether the current reimbursement is adequate or provide information to guide us toward a new payment methodology.

You have been very clear about the need for data. Is there any other data that can be helpful to Congress?

I commend the IDF and their patient members for responding to the call for improved data by sponsoring patient surveys and for the successful response rate by patients. I would like to see IDF regularly gather data and report to the committees of jurisdiction regarding changes in patient access to products and providers, as well as changes in health care status over time. I look forward to continuing to work with IDF and the many patients living with primary immune deficiency diseases.

Representative Jim McCrery, at IDF Capitol Hill Day 2006, was presented with the Distinguished Public Policy Award for leading the charge to fix the IVIG access problem. Pictured with him are Gail and Sydney Nelson, IDF Volunteers, and Marcia Boyle, President & Founder of IDF.
IDF Launches New Survey Research Center

IDF is proud to announce the launch of our new survey research center. Over the past decade, IDF has taken the lead in conducting national surveys of patients with primary immunodeficiencies, and medical professionals. Our survey data has been used effectively with government in quantifying the impact of the IVIG shortage several years ago, in helping change clinical trial design, and more recently in demonstrating the impact of Medicare reimbursement changes on patient care. Our survey results have been used by physicians to outline patient treatment and diagnosis experiences, as well as by industry and government to understand the demand for and efficacy of immunoglobulin replacement.

“Our survey data has been indispensable in furthering the understanding of primary immunodeficiencies by better defining the health status, treatment patterns and psycho-social experiences of our patients. Establishing our own survey research center will give us the ability to act quickly and collect critical data in response to our changing environment. I’m thrilled with the upcoming possibilities and the benefits that will result for our community,” Marcia Boyle commented.

The goal of the IDF research center is to provide the most current and accurate data on primary immunodeficiencies for advocacy, education and improved patient care. It will also provide a mechanism for ad hoc data collection and analysis on emerging issues and concerns, such as insurance reimbursement, the impact of live virus vaccinations, as well as the efficacy of treatments. The IDF survey research center will work with government, industry and the medical community to provide essential data for making decisions on a number of issues critical to our community, including access to care and appropriate therapies, research support and regulatory guidelines. IDF thanks Talecris Biotherapeutics for providing initial support for this critical effort, and we invite other stakeholders in our community to join us in participating in the efforts of this center.

This February, Christopher Scalphunes joined the IDF as the director of the new survey research center. Chris offers a wealth of experience from his ten years as a research analyst at a public policy center where he managed the survey research unit. If you want additional information about the center, Chris can be reached at 443.632.2551 or e-mail cscalchunes@primaryimmune.org.

New IDF Brochure Now Available!

**IDF—Your Key Resource, Your Best Advocate for Primary Immunodeficiency Diseases**

IDF is pleased to offer our new brochure. Our services, materials and programs are outlined as well as basic information on symptoms of primary immunodeficiency diseases. This brochure is offered free of charge and is perfect for distribution at physician offices, hospitals, health fairs—anyplace that will help spread awareness.

View online at www.primaryimmune.org

Alan Hobson to Speak at National Conference

IDF is pleased to announce that Alan Hobson will speak at the 2007 IDF National Conference in St. Louis, June 29th. Hobson has an incredible story to tell. After a decade of preparation, Alan Hobson’s first expedition to Mt. Everest missed the summit due to hurricane-force winds. He used his hard-won lessons to begin again, however his second Everest attempt missed the summit when the expedition’s lead climber became ill. After almost two decades Hobson finally stood on the highest point on the planet on his third attempt.

Three years after Everest, Alan faced his biggest mountain. He was diagnosed with leukemia and given less than a year to live. Today, Hobson has achieved an elite level of fitness after a blood transplant to eradicate the disease, and he is living proof of the power of persistence.

Don’t miss the opportunity to hear this compelling story of triumph and perseverance. Register today for the 2007 IDF National Conference. Visit www.primaryimmune.org to register online, or call 800.296.4433 for more information.
What about Clinical Trials?

IDF often receives requests for information about clinical trials. Clinical trials are research studies in volunteers to address specific health issues. These studies may be designed to learn more about a specific disorder, identify the causative gene, discover new therapies, or improve existing treatments. By participating in clinical trials, patients can be more involved in their own healthcare and potentially gain access to the newest treatments before they become widely available. Participation in clinical trials is also an important way to help others affected by a similar disease. Volunteer participation increases the body of information available to find out more about the causes, special features of the disorder and the most effective treatments for these rare diseases.

If you are interested in learning more about current clinical trials in the United States, check out the Web site offered by the U.S. National Institutes of Health and developed by the National Library of Medicine. The Web site www.clinicaltrials.gov lists information about clinical trials in an easy to search format. Searches can be carried out by diagnosis, treatments, geographic locations and various combinations of keywords.

Although the IDF does not review and/or endorse any particular clinical trial listed on this site, all trials on this site have received approval by institutional review boards. Frequently, these trials have also been authorized by the U.S. Food and Drug Administration, particularly if the trial involves testing responses to new pharmaceutical agents or new uses for existing treatments.

Choosing to participate in a clinical trial is an important personal decision. As with any decision concerning your disease and care, you should talk to your physician before joining any trial.

To find out more about current clinical trials visit: www.clinicaltrials.gov

IDF 2007 National Conference

Professional Medical Education Opportunity

Designed for healthcare professionals treating patients with a primary immunodeficiency disease, this program is a great opportunity for physicians and nurses to learn more about primary immunodeficiency diseases while earning continuing education credits. Residents, fellows, primary care physicians and pediatricians are all encouraged to attend this program on Friday, June 29, 2007 from 11:30 am – 5:15 pm.

This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of Washington University School of Medicine, Continuing Medical Education and the Immune Deficiency Foundation. Washington University is accredited by the ACCME to provide continuing medical education for physicians. Washington University designates this educational activity for a maximum of 5.0 AMA PRA Category 1 Credits™. The continuing nursing education activity has been approved by the Missouri Nurse’s Association, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation.

To register, visit www.primaryimmune.org.

For full details regarding registration, accreditation, credits, deadlines, etc., download the Professional Medical Education Program at: www.primaryimmune.org/conferences/conf_2007.htm.

Professional Medical Education Sessions

- Lunch and Welcome: H. James Wedner, MD, Washington University in St. Louis
- Introduction to Primary Immune Deficiency Disease: Howard Lederman, MD, PhD, Johns Hopkins School of Medicine
- Use of Laboratory Tests in Diagnosis of Primary Immune Deficiency Disease: Francisco (Tony) Bonilla, MD, PhD, Boston Children’s Hospital
- New Developments in the Understanding of Primary Immune Deficiency Disease: Hans D. Ochs, MD, University of Washington School of Medicine
- Treatment of Primary Immune Deficiency Disease through Bone Marrow Transplantation and Gene Therapy: Rebecca Buckley, MD, Duke University School of Medicine
- Immune Globulin Therapies: Melvin Berger, MD, PhD, Case Western Reserve and Rainbow Babies and Children’s Hospital; Debra Sedlak, CPNP, Duke University School of Medicine
The Immune Deficiency Foundation, founded in 1980, is the national patient organization dedicated to improving the diagnosis and treatment of patients with primary immunodeficiency diseases through research, education, and advocacy.

2007 CIRCLE OF SUPPORT
Baxter Healthcare Corporation
CSL Behring
Grifols
Octapharma
Talents Biotherapeutics

The Public Policy Programs

The IDF Patient Survey—Giving IDF a voice with lawmakers

When Medicare reduced intravenous immunoglobulin therapy (IVIG) reimbursement rates, IDF surveyed patients to discover how the reduction affected them, and presented the results. Closing the Centers for Medicare and Medicaid Services (CMS) to evidence of the hardships, the survey findings helped persuade CMS to issue final rules to terminate the temporary “prior administration-related services” add-on in 2007.

IDF appreciates all the patients who completed surveys. Your participation truly makes a difference.

IDF Capitol Hill Day—Raising awareness in Congress

In 2006 more than 60 IDF volunteers went to Capitol Hill to educate their members of Congress about primary immunodeficiency diseases. Hearing the volunteers’ stories proved invaluable in detailing the critical need for Congress to support initiatives for improved IVIG reimbursement rates and support for research funding.

Public Advocacy—IDF President speaks of the need for lifesaving therapy

Marcia Boyle, President of IDF, was a frequent voice on behalf of primary immunodeficiency patients who need IVIG. She testified at hearings at the House Ways and Means Subcommittee on Health on Medicare Reimbursement of Physician-Administered Drugs, the Advisory Committee Blood Safety and Availability, Department of Health and Human Services, and Public Meeting on Patient and Physician Concerns in Access to Intravenous Immunoglobulin (IVIG), conducted by Eastern Research Group, Inc. for the Department of Health and Human Services.

“...it is a national disgrace that the problem has persisted for more than seven years and little has been done to reverse access to IVIG in all states and end the suff ering that has devastated our community.”

President & IDF Founder
Marcia Boyle

Lobbying—Leadership & Grassroots Volunteer Advocacy Network

In 2006, IDF played a leadership role in mobilizing providers, advocates, industry and patients living with primary immunodeficiencies throughout the country to promote health care policy and legislation. We retained the services of Hart Health Strategies, a lobbying fi rm focused exclusively on health care legislation at the Federal Government level.

IDF established a formal Advocacy Network comprised of trained volunteers to share their stories, educate federal and state lawmakers and discuss the importance of current legislative issues with policymakers. The IDF Action Alert program, our web site’s advocacy tool, has mobilized our community to communicate directly with their members of congress.

The 2006 IDF Patient Survey found that 60% of patients on Medicare, who compared to their private pay insurance counterparts, are much more likely to report being AFV therapy postponed, treated inappropriately, and receiving no IVIG at all. As a direct result, they suffered signifi cantly more costs.

IDF Council of 114 Patient Advocates and IDF Action Alert, our online tool.

2006 highlights

President’s Message

If anyone had told me when we began the Immune Deficiency Foundation in 1980 that IDF would grow into such a vibrant, active organization, I probably would not have believed them... I never thought I would care for my son, who was diagnosed with X-linked Agammaglobulinemia. At that time, there was practically no information about this disease (in fact, the only family newsletter for the year 2006, was in healthy, married and pursuing his career and IDF couldn’t be busier.

2006 was filled with action, accomplishment, and challenges. Of particular pride was the establishment of the IDF Center of Excellence at Duke University, offering a home base to the young men and women with primary immunodeficiency diseases. We launched the Primary Immunodeficiency Alert Program to provide timely information and our innovative Career Counseling Service for Primary Immunodeficiency Diseases was published. Even the challenge to ensure access to intravenous immunoglobulin therapy was met by our community responding with characteristic drive—many of you literally marched up Capitol Hill to tell your stories.

Never has the need to continue our mission been clearer or more urgent and we can’t afford to waver about the road before us. As you read this 2006 recap and reaff irm your commitment to IDF, I want to share a quote from one of our patients to remind us all of the reason we are dedicated to the mission of IDF:

“I’m grateful I found your foundation. I already don’t feel so alone.”

Marcia Boyle

President & Founder
Immune Deficiency Foundation

2006 CIRCLE OF SUPPORT
In 2006, IDD opened the IDD Center of Excellence for Primary Immunodeficiency Diseases with the goal of increasing early diagnostic, treatment and disease management information can be received from expert immunologists, approximately 2,000 U.S. patients, family members and other affected families. IDD opens its doors to the country through this unique program, patient-specific questions and valuable diagnostic, treatment and disease management information can be received from expert immunologists.

“This service and the faculty of skilled clinical immunologists assisted me with a case that baffled me and my colleagues; the consulting immunologists provided lifelong saving answers.”

— Physician

“Through the IDD Center of Excellence, we will continue to pursue our goal to offer the best available options for rapid, accurate diagnosis of primary immunodeficiency diseases to explore the molecular causes, and to create the optimal and most effective treatments for these patients.”

— Roberta C. Israels, M.D., Center Director, Pediatric and Immunology at Duke University Medical Center

Approximately 2,000 IMMUNE DEFICIENCY DISEASE PATIENTS, FAMILY MEMBERS and OTHER AFFECTED FAMILIES received IDD help in 2007.

In 2006, IDD expanded its national clinical network to 61 collaborating academic medical centers throughout the country. IDD Blue Jean Immune Teams, signature fundraising and awareness project, work with expert immunologists, organizations, businesses and plasma centers, where donors are thanked for their “gift of life.”

“IT’s been wonderful to stay connected with these fellow patients...they all have special and amazing stories. Young, middle aged, close to my age... we are all one really! I am so honored that you have included me in your circle of help.”

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— Patient
Immune Deficiency Foundation

For twenty-seven years, the mission of the Immune Deficiency Foundation (IDF) has been to improve the lives of patients and their families affected by primary immunodeficiency diseases through research, education, and advocacy. All of our programs are designed to support this mission and meet our goals.

Patient and Family Programs

Patient Advocacy—IDF’s heart and focus

Every person living with primary immunodeficiency disease has unique needs and it is IDF’s goal to help them find and acquire the mission they need to live fully. IDF answers inquiries about diagnosis, treatment, and health insurance, as well as requests for information and peer support.

“I felt truly needed in the Immune Deficiency Foundation 14 years ago when I was newly diagnosed. This year I called about being denied treatment. IDF was there to help, support and advise.”

Peer Support—when it’s important to talk with someone who has been there

IDF connects patients and their families to share experiences, offer encouragement and support, and provide understanding. Volunteers, specially trained in peer support skills, are prepared to help others in the primary immunodeficiency community.

“My IDF peer support volunteer was a young mother with CVID who was my inspiration. She had so much energy and was so positive. She guided me and gave me the contact, determination and support needed for me to continue.”

Volunteerism—increasing awareness, raising funds, providing support

IDF could not exist without the volunteer network of dedicated IDF volunteers. Many serve as peer support volunteers, others advocate for public policy and plan educational meetings. Still others organize fundraising events throughout the country. IDF Blue Jeans for Healthy Genes, our signature fundraising and awareness project, is held annually in thousands of organizations, businesses and piano centers, where donors are thanked for their “gift of life.”

“It’s been wonderful to stay connected with these fellow patients… they all have special and amazing stories. Young, middle aged, close to my age… we are all really lucky. I am honored that you have included me in your circle of help.”

Patient Education—resources for living with primary immunodeficiency diseases

IDF provides information and treatment and management education to patients, caregivers and healthcare professionals about primary immunodeficiency diseases. In 2006, IDF Diagnostic and Clinical Care Guidelines for the Primary Immunodeficiency Diseases were published and gained in over 9,000 healthcare professionals and families. Our Guide for School Personnel: Primary Immunodeficiency Disease was eagerly welcomed by parents and school systems.

“Meeting others who are living with primary immunodeficiency disease and knowing that neither my husband nor I are alone in this really helps.”

Communications—keeping our community informed and setting the bar for the future

IDF publications and educational materials offer the most authoritative, up-to-date information for people living with primary immunodeficiency every day. In 2006, IDF Diagnostic and Clinical Care Guidelines for the Primary Immunodeficiency Diseases, the first comprehensive guidelines in these diseases, was published and given to over one million hits each month. The IDF Advocate, our traditional newsletter is published three times a year and has a circulation of 20,000.

Medical Programs

New IDF Center of Excellence—Duke University Medical Center

In 2006, IDF opened the IDF Center of Excellence for Primary Immunodeficiency Diseases with the goal of increasing early diagnosis and improving treatment and care for patients at Duke University Medical Center. The Center offers the services of some of the world’s leading experts and state of the art facilities focusing on research and clinical care of primary immunodeficiency diseases.

“The new IDF Center of Excellence, as we will continue to pursue our goals to offer the best available options for accurate, diagnostic and treatment for many patients in Duke University Medical Center. The Center offers the services of some of the world’s leading experts and state of the art facilities focusing on research and clinical care of primary immunodeficiency diseases.”

Consulting Immunologist Program—Valuable Advice from Expert Immunologists

Since 1996, IDF’s Consulting Immunologist Program has provided free expert consultations to any physicians requiring assistance in primary immunodeficiency diseases. Through the unique program, patient-specific questions and valuable diagnostic, treatment and disease management information can be received from expert clinical immunologists.

“This service and the faculty of skilled clinical immunologists assist me with a case that baffled me and my colleagues; the consulting immunologists provided life saving answers.”

LaDene Visiting Professor Program—Promoting Medical Knowledge and Awareness

The Visiting Professor Program contributes to and promotes medical knowledge and educational awareness of primary immunodeficiency diseases in America’s teaching hospitals. Coordinated through IDF, foremost clinical immunologists lead hospitals grand rounds and other educational activities, such as medical resident conferences, for their healthcare professionals.

“The Visiting Professor has added significantly to the value of our educational curriculum. His approach … was clearly presented and easily applied. He answered questions effectively, and challenged the audience appropriately. We truly valued every aspect of his visit.”

US Immunodeficiency Network—Advancing Scientific Knowledge

IDF administers the US Immunodeficiency Network, an international consortium established to advance scientific research in the primary immunodeficiency diseases through peer review, research grants, education and mentoring programs. OI administrators and a patient registry (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.

“We are grateful to be part of such an outstanding program that has had a significant effect on the care of patients with primary immunodeficiency disease.”

Advancing IDF Education—new publications

In partnership with expert immunologists, IDF has developed and distributed the IDF Diagnostic & Clinical Care Guidelines for Primary Immunodeficiency Diseases. The IDF Medical Advisory Committee took the lead in revising the fourth edition of the Patient & Family Handbook for Primary Immunodeficiency Diseases that will be available in June 2007. One of the key activities for the IDF Nurse Advisory Committee was to report and revise the IDF Guide for Nurses in Immunodeficiency to include new replacement therapy options, also available in June.

In 2006, nine USIDNET research sub-contracts were awarded an total of $7.58 million, which represented a more than 40% over 2005, with almost 90 requests last year.

Growing in popularity, the number of Consulting Immunologist Program requests has increased more than 60% over 2005, with almost 10,000 requests last year.

The Immune Deficiency Foundation wishes to thank the Board of Trustees, Medical Advisory Board, Nurse Advisory Committee, volunteers, staff, and our many generous supporters.
Immune Deficiency Foundation
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**Patient and Family Programs**

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Peer Support—when it’s important to talk with someone “who has been there”
IDF connects patients and their families to others who understand their experiences, and provides support. Volunteer training in peer support skills is prepared to help others in the primary immunodeficiency community.

“My IDF peer support volunteer was a young mother with CVID who was my inspiration. She had so much energy and was so eager to learn. She was an excellent resource for me and my family.”

Volunteerism—increasing awareness, raising funds, providing support
IDF could not exist without the volunteerism of its network of dedicated IDF volunteers. Many serve as peer support volunteers, others advocate for public policy and plan educational meetings. Still others organize fundraising events throughout the country. IDF Blue Jeans for Healthy Skin, our signature fundraising and awareness project, works to identify families organizations, businesses and plasma centers, whose donors are thankful for their “gift” of life.

“It’s been wonderful to stay connected with these fellow patients…they all have special and amazing stories. Young, middle-aged, close to my age…we are all so lucky! I am honored that you have included me in your circle of help.”

**Medical Programs**

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“Through the IDF Center of Excellence, we will continue to pursue our goals to offer the best available options for rapid, accurate diagnosis of primary immunodeficiency diseases, to deploy the molecular causes, and to identify the optimal and most effective treatments for these patients.”

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“The Visiting Professor visit added significantly to the value of our educational curriculum. The approach…was clearly presented and easily applied. He answered questions effectively, and challenged the audience appropriately. We truly valued every aspect of his visit.”

IDF published eight national and international conference proceedings on primary immunodeficiency diseases. These educational materials were distributed in over 2,000 hospitals in the United States in 2007.

IDF exhibits at eight national and international conferences.

IDF administered the US Immunodeficiency Network, an international consortium established to advance scientific research in the primary immunodeficiency diseases through peer-reviewed, research grants, education and membership programs. OIHP and cell therapy, and patient registry. USIDNET is funded by the National Institutes of Health 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.

“Appropriately, USIDNET exists to help patients, the number of Consulting Immunologist consultations increased more than 60% over 2005, with almost 400 requests last year.”

**Medical Programs**

**IDF Volunteer**

The Immunodeficiency Foundation welcomes is to the Board of Trustees, Medical Advisory Board, Nurse Advisory Board, volunteers, staff and our many generous supporters.

**IDF Volunteer**

Approximately 2,000 patient, family

consultations were provided this year. IDF

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"Through the IDF Center of Excellence, we will continue to pursue our goals to offer the best available options for rapid, accurate diagnosis of primary immunodeficiency diseases, to deploy the molecular causes, and to identify the optimal and most effective treatments for these patients.”

**医用程序**

**新IDF中心的卓越中心—杜克大学医学中心**

在2006年，IDF开放了IDF卓越中心，致力于对疾病的早期诊断和治疗，以及对杜克大学医学中心的患者提供服务。该中心提供了一系列的诊断、治疗和疾病管理信息，帮助医生和研究人员更好地理解这些疾病的分子基础，以及在临床和研究中应用这些信息。

“我们通过IDF卓越中心，将继续努力为患者提供最佳的解决方案，以加快准确的疾病诊断和治疗，以及对疾病的研究和临床应用，特别是针对免疫缺陷疾病。”

**咨询免疫学家项目—有价值的专业建议**

自1998年以来，IDF咨询免疫学家项目提供了免费的专家咨询服务，任何寻求协助的临床免疫学家都可以参与。通过这一独特的项目，可以为患者提供个性化的具体问题和研究的详细信息，从而获得专家的临床建议。

“这种服务和我们参与的临床免疫学家团队都为我提供了有价值的建议。在我遇到难题时，他们提供了至关重要的帮助。”

**LeaBlain访问教授项目—促进医学知识和意识**

访问教授项目有助于促进医学知识和教育意识，特别是关于免疫缺陷疾病，这些疾病在美国的医院中非常常见。通过IDF，世界上最顶尖的临床免疫学家在医院的grand rounds和其他教育活动中授课，如医学实习生会议，为他们的医疗专业人员提供了价值。“访问教授的来访极大地提高了我们教育课程的深度。他的方式...清晰明确，易于应用。他回答了问题并挑战了观众。我们非常珍惜他来访的每个方面。”

**IDF展示了八个国际和国际会议的简介。**

IDF在8个国家和国际会议上展示了其研究成果，并向2000多家医院分发了这些材料。在2007年，共有27份研究子合同被授予，并且自2003年10月以来，总共获得了约270万美元的子合同。

**美国免疫缺陷网络—促进科学知识**

IDF管理的美国免疫缺陷网络是一个国际联盟，旨在通过资助科学研究、意大利科学研究院的研究计划和临床免疫缺陷疾病的教育和研究项目，提高和促进医疗领域的科学知识。OIHAP和细胞治疗，以及患者登记，USIDNET由美国国家过敏和传染疾病研究所和美国国家儿童健康和人类发展研究所资助，这些机构是美国国家卫生研究院的组成部分，一个联邦部门，负责国家卫生和社会服务部。

“在2006年，IDF开展的咨询免疫学家项目被授予了60%以上的增长，共有400多次申请。”

**IDF志愿者**

“它的伟大！接触其他生活与免疫缺陷疾病有关的人们，我更加自信和坚定。我再次感谢你让我成为你们的帮助之圈的一员。”

“这是一次伟大的经历！与生活在免疫缺陷疾病中的人们交流，并且知道，无论是我丈夫还是我，我们都没有被打败。我非常荣幸能够被你们包括在内。”

**患者及家庭程序**

患者倡导—IDF的中心和焦点
每个人与原发性免疫缺陷病的患者都有独特的需要，这就是为什么IDF致力于帮助他们和他们的家庭找到满足这些需求的资源。IDF回答了关于诊断、治疗和健康保险的问题，以及对信息和同伴支持的需求。

“I first heard about the Immune Deficiency Foundation 14 years ago when I was newly diagnosed. This year when I called about being denied treatment, ID was there to help, support and advise.”

同伴支持—与“已经经历过的人”谈谈
IDF将患者及其家人与其他人联系起来，这些其他人可以分享他们的经历和经历，提供支持。志愿者接受专业的培训，以帮助其他人，包括在免疫缺陷疾病社区。

“My IDF peer support volunteer was a young mother with CVID who was my inspiration. She had so much energy and was so eager to learn. She was an excellent resource for me and my family.”

志愿者—增加意识，筹集资金，提供支持
IDF将无法生存如果没有其网络中致力于IDF的志愿者。许多人作为同伴支持的志愿者，其他人则为公共政策和教育活动提供支持。还有些人组织筹款活动，遍及全国各地。IDF蓝色牛仔裤为健康皮肤，我们的签名筹款和意识项目，寻找与免疫缺陷疾病相关的组织、企业和其他地方，其捐赠者感谢他们“生命的礼物”。

“It’s been wonderful to stay connected with these fellow patients…they all have special and amazing stories. Young, middle-aged, close to my age…we are all so lucky! I am honored that you have included me in your circle of help.”
P U B L I C   P O L I C Y   P R O G R A M S

The IDF Patient Survey—Giving IDF a voice with lawmakers

When Medicare reduced intravenous immunoglobulin therapy (IVIG) reimbursement rates, IDF surveyed patients to discover how the reduction affected them and provided the results. Closing the Centers for Medicare and Medicaid Services (CMS) to evidence of the hardships, the survey findings persuaded parliament to issue final rules to continue the temporary "pre-administration-related services" add-on for IVIG. The IDF Patient Survey—Giving IDF a voice with lawmakers.

IDF appreciates all the patients who completed surveys. Your participation truly makes a difference.

IDF Capitol Hill Day—Raising awareness in Congress

In 2006 more than 60 IDF volunteers went to Capitol Hill to educate their members of Congress about primary immunodeficiency diseases. Hearing the volunteers' stories proved invaluable in convincing lawmakers to support initiatives for improved IVIG reimbursement rates and support for research funding.

Public Advocacy—IDF President speaks of the need for lifesaving therapy

Marcia Boyle, President of IDF, was a frequent voice on behalf of primary immunodeficiency patients who need IVIG. She testified at hearings at the House Ways and Means Subcommittee on Health, Medicare-Reimbursement of Physician-Administered Drugs, the Advisory Committee on Blood Safety and Availability, Department of Health and Human Services, and Public Advocate—IDF President speaks of the need for lifesaving therapy.

Lobbying—Leadership & Grassroots Volunteer Advocacy Network

In 2006, IDF played a leadership role in mobilizing providers, advocates, industry and persons living with primary immunodeficiencies throughout the country to promote health care policy and legislation. We retained the services of Hart Health Strategies, lobbying firms focused exclusively on health care legislation at the Federal Government level.

IDF-established a formal Advocacy Network comprised of trained volunteers to share their stories, educate federal and state legislators and discuss the importance of current legislative issues with policymakers. The IDA Action Alert program, our web-based advocacy tool, has mobilized our community to communicate directly with their members of congress.

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- Infections
- Increased use of antibiotics
- Hospitalizations

The difference in number and magnitude of health problems experienced by PID patients in direct correlation with their difficulties in obtaining IVIG.

IDF appreciates all the patients who completed the surveys. Your participation truly makes a difference.

IDF Capitol Hill Day—Raising awareness in Congress

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“It is a national disgrace that this problem has persisted for over two years and little has been done to restore access to IVIG for patients with primary immunodeficiency diseases. We launched the Primary Immunodeficiency Patients’ Health and Safety Network, a Facebook group with 180 patients with primary immunodeficiency diseases. We launched the Primary Immunodeficiency Network’s Guide to Live Longer and Better and 118 Members of Congress were briefed by IDF volunteers.

IDF’s Capitol Hill Day was filled with action, accomplishment, and challenges. Of particular pride was the establishment of the IDF Center of Excellence at Duke University, offering state-of-the-art care for primary immunodeficiency patients and their families. The Center would provide timely information and our innovative “Primary Immunodeficiency: Essentials for Global Health Care Professionals” was published. Even the challenge to remove access to intravenous immunoglobulin therapy was met as our community responding with characteristic drive—many of you literally marched up Capitol Hill to tell your stories.

Never has the need to continue our mission been clearer or more urgent and I am encouraged and excited about the road before us. As you read this 2006 recap and mirror your commitment to IDF, I want to share a quote from one of our patients to remind us all of the reason we are dedicated to the mission of IDF:

“I am grateful I found your foundation. I already don’t feel alone.”

We look forward to 2007 when we will see the IDF Center of Excellence at Duke University open its doors, leading the way to better care for all primary immunodeficiency patients. The IDF’s mission is healthy, married and pursuing his career and IDF couldn’t be busier. 2006 was filled with action, accomplishment, and challenges. Of particular pride was the establishment of the IDF Center of Excellence at Duke University, offering state-of-the-art care for primary immunodeficiency patients and their families. The Center would provide timely information and our innovative “Primary Immunodeficiency: Essentials for Global Health Care Professionals” was published. Even the challenge to remove access to intravenous immunoglobulin therapy was met as our community responding with characteristic drive—many of you literally marched up Capitol Hill to tell your stories.

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With your support and encouragement, IDF will continue to address the needs of patients with primary immunodeficiency diseases and meet future challenges. Thank you to everyone involved with IDF.

Marcia Boyle
President & Founder
Immune Deficiency Foundation

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The Immune Deficiency Foundation is a publicly supported, non-profit organization as described under Section 501 (c) (3) of the Internal Revenue Code of 1986, an exempt organization under Section 501 (c) (3) of the Internal Revenue Code of 1986, and therefore, eligible to receive grants from public and private foundations, as well as individual contributions.

The National Patient Organization for Primary Immunodeficiency Diseases

IDF: The patient’s voice in primary immunodeficiency diseases.

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Marcia Boyle
President & Founder
Immune Deficiency Foundation

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New Youth Education Programs

Educational Sessions for Children and Youth at IDF National Conference

You don’t have to be of voting age to get your needs met at the IDF 2007 National Conference. The conference is packed with age specific programming that is sure to interest and educate the under 18 crowd.

We asked participants in the teen group what they wanted. Their requests were loud and clear—they want detailed information about primary immunodeficiencies. To meet their needs, IDF is offering:

- Immune System Basics: Learn about B-cells, T-cells, Phagocytes and complement
- Primary Immunodeficiency Disease & Treatment Options
- Introducing Genetics
- Deal with It: Learn about identifying and expressing your feelings and coping techniques
- Ask the Expert Seminar: A team of medical personnel answer questions

The teen group will also attend the presentation by Alan Hobson who tells an extraordinary story about his grueling attempts to reach the summit of Mt. Everest and his subsequent battle with acute leukemia. Hobson discusses how to learn from setbacks, adapt to shifting priorities and focus on exceptional excellence—a valuable message for all ages.

The 6 to 11 age group will be learning about similar, age appropriate topics:

- Our Immune System: Lesson and activities
- Kid’s Clinic: Hands-on clinic to learn about heart rate, body temperature, blood pressure, wound care
- Clean Hands, Healthy Kids: Learn how to be a germ-buster
- Body Works: Learn about the major organs in your body. Make a life-size model and add the organs.
- I Can Do It: Learn about expressing your feelings and coping techniques

On Friday, all youth ages 6-17 years, will visit the St. Louis Science Center. They will have the opportunity to see an exhilarating film about Mt. Everest at the OmniMax Theater, view the Marvel Comics display and all of the science exhibits. That night, a Wild Safari Adventure Party, complete with food, games, activities and videos, is planned.

To register for the IDF 2007 National Conference, visit www.primaryimmune.org or call 800.296.4433.

Volunteers in Action

Mayor J. Turner presents a proclamation to Yvette Shorten, a dedicated IDF Volunteer, and her son Jermaine at a city council meeting on April 17, 2007. The proclamation declared April as Primary Immunodeficiency Disease Awareness Month in Huntsville, Texas.

Terri Lowell (pictured left) and Evelyn Maselli, long-time IDF Volunteers, hosted the 7th Annual Wines of the World event in West Haven, Connecticut on Friday, April 13, 2007. The event offered participants the opportunity to sample wines from around the world, enjoy music and bid on auction items, while creating awareness about primary immunodeficiency diseases and raising funds that support the mission of IDF.
“These are Precious Moments”

Zina and Randy Berryhill, like most parents, have to keep running just to stay in place. Living in Chicago, with their three sons, Randy Jr., 14, Ramzi, 11, and five year old Raymus, affectionately called RayRay, they juggle their schedules to keep up with all the activities that three children can create. However, they are never too busy to appreciate the truly important things in their lives. Their family is celebrating a special event that is over five years in the making—the adoption of RayRay has finally been made official.

RayRay came into the Berryhill’s life as a foster child in 2001 when he was just six weeks old. Zina describes him as the “cutest little guy” but something was wrong. He coughed all the time and his blood work showed that there were problems. He spent a month in the hospital, but still no cause was identified. Zina described her frustration during that time. “We took him to the hospital every week and all I wanted was for the doctors to ‘fix him’. I became a raving advocate- things were just not moving fast enough!”

Ultimately, a diagnosis was made for RayRay, Adenosine Deaminase Deficiency. This is a type of Severe Combined Immune Deficiency (SCID) caused by mutations in a gene that encodes an enzyme called adenosine deaminase (ADA). ADA is essential for the metabolic function of a variety of body cells, but especially T cells. The absence of this enzyme leads to an accumulation of toxic metabolic by-products within lymphocytes that cause the cells to die. ADA deficiency is the second most common cause of SCID, accounting for 15% of cases. Babies with this type of SCID have the lowest total lymphocyte counts of all, and T, B and NK-lymphocyte counts are all very low.

Today, RayRay is a typical five-year old. He loves being read to and playing in the park with his brothers. Zina points out that Randy Jr. and Ramzi play a big part in RayRay’s healthcare. “The whole family, including his grandmother, aunt and niece, is involved in RayRay’s healthcare treatment. We do whatever it takes to take care of him.”

Zina admits that there are hard days, but they find ways to get through the difficult times. For example, it is now a rule at the Berryhill home that nobody cooks dinner on the often hectic and stressful days that RayRay gets his infusions. Infusion days are designated as a “take-out” mealtime, giving a break to the cook.

Zina keeps a positive attitude and finds joy in everyday life. “I just tell myself to be strong, this is the journey God put me on and these are precious moments. My life is dedicated to my family and I want to do the best I can.”

Zina and Randy Sr. are IDF volunteers. They have been involved with the Foundation since 2002 when they attended an IDF Family Retreat and since then, have helped at the national conferences and other educational meetings. They have been advocates for IDF Capitol Hill Day and serve as Peer Support Volunteers.
CSL Behring Reports Progress on Global Implementation of Name Change

CSL Behring provided an update on its global name change, involving as many as 30 products in each of 70 countries worldwide. The new name, CSL Behring, is now registered in the U.S., Germany, Switzerland and Canada, with other countries following over the next several months. The renaming program, announced by CSL Behring's parent organization, CSL Limited, last year, will present a consistent and compelling view of the company operating in new and established markets around the world. The quality, type and volume of products that CSL Behring produces are not impacted by this name change. CSL Behring is currently in the process of notifying the respective national health authorities regarding the license transfer. No changes to product names will occur. Excerpted from CSL Behring News Release, January 8, 2007

Grifols Announces FDA Approval of its Next Generation IVIG Preparations—Flebogamma® 5% DIF

Grifols announced that it has received approval from the US Food and Drug Administration (FDA) to market its next generation immune globulin (IVIG), called Flebogamma® 5% DIF (dual inactivated and nano-filtered). Flebogamma® 5% DIF has been under development for more than a decade, starting from the early stages of product planning, through construction of the new production facility, and finally resulting in FDA licensure. Flebogamma® 5% DIF offer physicians and patients a new standard in terms of IVIG safety and purity through two distinct pathogen inactivation processes and a proprietary 20 nanometer filtration step. At the same time, Grifols' new production facilities and manufacturing processes will have the potential to increase the yield of IVIG. Excerpted from Grifols News Release, January 15, 2007

Talecris' Product Integrity Enhanced With Environmentally-friendly Shipping Containers

Talecris Biotherapeutics has integrated environmentally-friendly insulated shipping containers into its cold chain supply. The fully degradable Control Temp Blue™ container will provide enhanced temperature protection necessary to safely transport Talecris' critical care treatments for people with life-threatening disorders. Talecris' products are delicate and temperature-sensitive, necessitating extra care during packaging and distribution to help ensure the safety and efficacy of the products. Control Temp Blue sets an industry standard for its environmentally-friendly design. Talecris adopted this unique packaging solution to minimize environmental impact and reduce waste. Excerpted from Talecris News Release, February 15, 2007

Grifols Announces Expansion of US Manufacturing Capacity

Grifols announced the decision of its Executive Committee to validate the “MiniFrac” Facility which will provide additional capacity thereby allowing the company to increase the overall plasma throughput at its Los Angeles manufacturing complex by as much as 700,000 liters. This will result in increased production of Grifols' propriety hemophilia therapies, immune globulins, and albumin. Grifols' management estimates that validation and FDA approval will take approximately two years after which the MiniFrac Facility will be fully operational. Excerpted from Grifols News Release, March 13, 2007

URGENT: Biologic Withdrawal ZLB Behring Voluntarily Initiates Withdrawal

URGENT: BIOLOGIC WITHDRAWAL INFORMATION
Initiated by: ZLB Behring
Event Id: 128
Event Date: 02-21-2007
Therapy: Carimune® NF
Packaging: -
Expiration Date: 11-26-2009

ZLB Behring L.L.C. has voluntarily decided to initiate a withdrawal of Carimune® NF, lot 43017-00016, with expiration date of 11/26/09. This action is being taken with the knowledge of the Food and Drug Administration. During routine inspection of undistributed lots, vials with glass particles were identified. The subsequent investigation was expanded to include inventory potentially affected by this issue. There are no reports of glass in this lot, however, they are withdrawing lot 43017-00016 as a precautionary measure.

If you need assistance, please call Stericycle, Inc. at 1-888-UPDATE-U.
Immune Deficiency Foundation
Upcoming Events

May 5, 2007
Operation Outreach
Buffalo Transportation Pierce Arrow Museum
Buffalo, NY
Mark Ballow, MD and Heather Lehman, MD – Immune System Basics, PIDD & Treatment Options
Lynne Szott, CSL Behring – Protecting Your Health Insurance
For more information contact Diana Gill at 800-296-4433 or dgill@primaryimmune.org.

May 18-22, 2007
The American Association of Immunologists
Miami Beach, FL
IDF will be an exhibitor

May 19, 2007
Operation Outreach
San Antonio Botanical Gardens
San Antonio, TX
Anthony Infante, MD – Immune System Basics, PIDD & Treatment Options
Lynne Szott, CSL Behring – Protecting Your Health Insurance
For more information contact Diana Gill at 800-296-4433 or dgill@primaryimmune.org.

June 2-7, 2007
Infusion Nurses Society Annual Meeting
Orlando, FL
IDF will be an exhibitor

June 6, 2007
Milwaukee Area Support Group for Parents of Children with Primary Immune Deficiency Disorders
Milwaukee, WI
6:30 to 8:30 p.m.
For more information contact Linda Keegan at linda.keeganwi@aol.com.

June 9, 2007
2nd Annual IDF Charity Golf Tournament – Hosted by Biolife Plasma Services
Coldwater Golf Course
Ames, IA
1:00 p.m.
For more information contact Alison Burlage at 510-233-2510

June 14-15, 2007
Mt. Sinai Medical Center
New York, NY
Dr. Luigi Notarangelo will present at Grand Rounds as the LeBien Visiting Professor.
For more information contact Tamara Brown at 800-296-4433 or tbrown@primaryimmune.org

June 28-30, 2007
IDF 2007 National Conference
Renaissance Grand Hotel
St. Louis, MO
For more information contact Diana Gill at 800-296-4433 or dgill@primaryimmune.org. You can also visit www.primaryimmune.org and click on the conference link at the top of the page to find out more.

September 5, 2007
Milwaukee Area Support Group for Parents of Children with Primary Immune Deficiency Disorders
Milwaukee, WI
6:30 to 8:30 p.m.
For more information contact Linda Keegan at linda.keeganwi@aol.com.

September 8, 2007
Patient Education Meeting
Hoagland Pincus Conference Center
Shrewsbury, MA
For more information contact Towma Rastad at allissalec@yahoo.com

September 15, 2007
Patient Education Meeting
Milwaukee County Zoo
Milwaukee, WI
For more information contact Linda Keegan at linda.keeganwi@aol.com.

October 27-30, 2007
American Association of Pediatrics
San Francisco, CA
IDF will be an exhibitor

November 9-14, 2007
American College of Allergy, Asthma & Immunology
Dallas, TX
IDF will be an exhibitor

December 5, 2007
Milwaukee Area Support Group for Parents of Children with Primary Immune Deficiency Disorders
Milwaukee, WI
6:30 to 8:30 p.m.
For more information contact Linda Keegan at linda.keeganwi@aol.com.

Sign-up to Receive IDF’s E-Newsletter—Primary Immune Tribune
To receive a free subscription of Primary Immune Tribune please visit www.imakenews.com/idf fill out the necessary fields under the “subscribe” section on the left-hand side, and click “submit.”

For questions e-mail us at enewsletter@primaryimmune.org, or phone us at 800-296-4433

Primary Immune Tribune
E-newsletter of the Immune Deficiency Foundation
Plan a Blue Jeans for Healthy Genes Day

Become involved and 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 at the same time.

Order your free Blue Jeans for Healthy Genes kit to get started. The kit contains all the materials you need to make this project successful in any setting. To find out more, contact IDF at 800.296.4433, or e-mail Kathy Antilla, Director of Education and Volunteer Development, at Kantilla@primaryimmune.org.

With Gratitude

The Immune Deficiency Foundation gratefully acknowledges those who generously contribute to the organization to celebrate the memory of someone who has died or to honor someone special.

Gifts In Memory Of
Norman Asselin
Allene C. Atwood
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Nicholas and Dylan Sutton
Michael F. Thompson
Dr. Richard Wasserman

These donations help IDF to improve the diagnosis and treatment of patients with primary immune deficiency diseases through research, education and advocacy. If you would like to make a donation, please go on our Web site, www.primaryimmune.org, click the “How You Can Help” tab and use the secure online server. You can also contact us in any of the following ways:

Phone: 800.296.4433 or 410.321.6647 E-mail: idf@primaryimmune.org Mail: IDF, 40 W. Chesapeake Avenue, Suite 308, Towson, MD 21204

Combined Federated Campaign #9808
IDF 2007 National Conference
June 28-30, 2007
Renaissance Grand Hotel
St. Louis, MO
Register Today!
www.primaryimmune.org
800-296-4433

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