IDF Center Of Excellence Dedicated At Duke University

A special dedication ceremony was held on October 28, 2006, at Duke University Medical Center for the opening of the Immune Deficiency Foundation (IDF) Center of Excellence for Primary Immunodeficiency Diseases. The IDF, through a generous grant from Talecris Biotherapeutics, has collaborated with Duke to make this center available to patients and physicians with the goal of increasing early diagnosis and improving treatment and care for patients with primary immunodeficiency diseases (PIDD). The center, housed in the Duke University Medical Center, includes some of the world’s leading experts and state-of-the-art facilities focusing on the research and clinical care of PIDD.

“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 define the molecular causes, and to ensure the optimum and most effective treatments for those patients,” said Rebecca H. Buckley, MD, center director and the J. Buren Sidbury Professor of Pediatrics and Professor of Immunology at Duke University Medical Center.

“Diagnosis of a primary immunodeficiency often takes as long as nine years, primarily because of a lack of familiarity with these diseases by both health care providers and patients. Working collaboratively with IDF and Talecris, we believe this Center of Excellence will go a long way toward improving awareness of PIDD, among referring physicians, speeding diagnosis, and providing the optimal therapy more quickly for our patients.”

The new IDF Center of Excellence at Duke includes a staff of more than 21 physician-scientists, nurses, post-doctoral fellows, technicians, and other health care professionals who focus on advancing the diagnosis and therapy of PIDD.

continued on pg.2.

Two patients, Nicholas Schwab and H. Burns Blackwell, who will be beneficiaries of the new center, presented Dr. Buckley with flowers and shared their views on how the center will support efforts for those with primary immunodeficiencies to receive the best possible care, and optimize opportunities for improved quality of life.
**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.

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**IDF Advocate**

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**“IDF Center Of Excellence...”, cont’d.**

Distinguishing features of the center include:

- having the largest number of faculty in the U.S. with expertise in primary immunodeficiency diseases.
- developing sophisticated diagnostic testing utilized by many outside physicians.
- being the largest center in the United States performing life-saving T cell-depleted haploidentical bone marrow stem cell transplants for infants with severe combined immunodeficiency (SCID).
- being the largest center in the world performing life-saving thymic transplants for infants with complete DiGeorge syndrome.
- treating a large number of patients with antibody deficiency with intravenous or subcutaneous immunoglobulin.

Dr. Blaese spoke about achieving IDF’s continuing goals through Centers of Excellence. “This IDF Center of Excellence is an especially gratifying collaboration that brings together the strengths and commitments of IDF with those of a leading academic institution providing sophisticated diagnostic testing and therapy. Whenever we see programs that expand and improve care for the primary immunodeficinet community, IDF will be there doing everything it can to facilitate the process. We are extremely grateful to Duke University Medical Center and Talecris.”

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Rebecca H. Buckley, MD, Center Director and Professor of Immunology at Duke University Medical Center is introduced by A. Wesley Burks, MD, Chief, Division of Pediatric Allergy and Immunology, both of Duke University Medical Center

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Steve Petteway, Senior Vice President for Development & Research at Talecris Biotherapeutics, spoke of the importance of industry support for the primary immunodeficient community and Talecris Biotherapeutics’ partnership with IDF and Duke University Medical Center.

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Joseph W. St. Geme, III, MD, Chair, Department of Pediatrics, Duke University Medical Center discussed the Center’s role in increasing early diagnosis and improving care for patients with primary immunodeficiency diseases.
IPOPI Meets in Budapest

The International Patient Organization for Primary Immunodeficiencies (IPOPI) held its Biennial Meeting in Budapest, Hungary this fall, joining the International Nursing Group for Immunodeficiencies (INGRID) and the European Society for Immunodeficiencies (ESID) at the Biennial ESID/IPOPI/INGID Congress. Over 1,000 medical professionals, nurses, patients and other professionals attended these meetings. IDF was well represented at the meeting with Marcia Boyle, President and Founder, and Kathy Antilla, Director of Education and Volunteer Services, participating in the IPOPI meetings, and Isaac Antilla taking part in the Young Adult sessions. R. Michael Blaese, MD, IDF’s Medical Director, attended the ESID meetings. Kathy Antilla has represented IDF for the past two years on the IPOPI board, and Marcia Boyle will now serve on the IPOPI board for the next two years.

IPOPI is the international organization whose members are National Member Organizations (NMOs) for the primary immunodeficiencies. Its objectives are to work to improve access to early diagnosis, optimal treatment and care, and to promote the establishment of and support the work of NMOs. Its purpose is to unite the experience, expertise, resources and influence of its members to achieve worldwide improvement in the care and treatment of patients with primary immunodeficiencies.

In 1988, Bob LeBien, a member of the IDF Board of Trustees, met with Dr. Helen Chapel in England and discussed the idea of an international patient organization for primary immune deficiency diseases. These discussions led to Dr. Chapel inviting IDF to help initiate a meeting of other patient groups in 1990 at the European Group for Immunodeficiencies meetings in Oxford, England. This initial meeting was attended by twenty patient representatives from thirteen countries, including Bob and Sara LeBien and Marcia Boyle. In 1992 at the ESID meetings in Lugano, Switzerland, the International Patient Organization for Primary Immunodeficiencies was formally established. Between the first and second meetings of IPOPI, a number of new patient organizations were created in other countries. At the meeting in Lugano, 39 patient representatives attended from seventeen NMOs. IPOPI now has 26 NMOs. Bob served as Chair of the Executive Committee for three terms and was voted “President for Life” in 1998.

Since its beginnings, IPOPI has come a long way. During the past two years, the IPOPI Strategic Plan was revised, IPOPI played the leading role in the development of the EU Consensus Conference in 2006, and is leading the application to the World Health Organization for the re-instatement of immunoglobulins to the Essential Medicines List.

For more information about IPOPI, please visit www.ipopi.org.

IPOPI Board Members
(back row L to R) Sven Fandrup, Jose Drabwell, Bianca Pizzera, Rev. Stephen Baxter, (front row L to R) Eva Brox, Teresa Espanol, MD, Marcia Boyle, Joy Rosario, Vicki Modell, Martine Pergent

IDF Scholarship Program

The Immune Deficiency Foundation (IDF) awards scholarships to undergraduate students living with primary immune deficiency diseases. IDF is honored to assist students who have lived with the challenges of primary immune deficiencies and plan on completing their secondary education. The IDF Scholarship Program is open to patients with a primary immune deficiency as classified by the World Health Organization. It is intended for undergraduate students attending or entering college or a technical training school.

The application is now available online at www.primaryimmune.org. On the right-hand side of the homepage, click “2007 IDF Scholarship Available,” then click “Download the IDF Scholarship Application” on the subsequent page. For additional information contact Tamara Brown, Director of Medical Programs at 800-296-4433, or tbrown@primaryimmune.org.

The 2007 IDF Scholarship Program consists of unrestricted donations from the Eric C. Marder Scholarship Fund and from the Jerry Voyles IDF Scholarship Fund, which is supported through unrestricted educational grants from Baxter Healthcare Corporation, Grifols, Octapharma, Talecris Biotherapeutics and ZLB Behring.
IDF Survey Helps Persuade CMS to Temporarily Stop Reductions for IVIG Medicare Payments

The Immune Deficiency Foundation (IDF) patient survey helped persuade the Centers for Medicare and Medicaid Services (CMS) to issue final rules that grant a critical reprieve for patients with primary immune deficiency diseases (PIDD). On November 1, 2006, CMS issued a ruling that will continue the temporary “preadministration-related services” add-on for IVIG in 2007 for both physician services and hospital outpatient department (OPD) reimbursements for IVIG. CMS had established this additional payment for IVIG in 2006 to compensate physicians and hospital OPDs for extra resources needed for locating and obtaining appropriate IVIG products. It was also used for scheduling patient infusions during a period “where there may be temporary instability.” CMS also withdrew another separate proposal to reduce Medicare’s payment for IVIG in the hospital OPD setting.

In its final rules, CMS cited the patient survey as offering evidence of the hardships that many PIDD patients have had to deal with because of reductions in Medicare payments for IVIG. Some of the findings from the survey include patients reporting that they have had to change the site of their infusions, postpone infusions, increase intervals between infusions, and reduce dosage of IVIG as the result of changes in Medicare reimbursement methodology for IVIG.

IDF wishes to thank the over one thousand PIDD patients who took the time to respond to our survey this year. We believe that the survey’s results made the difference in providing hard, empirical data that CMS needed to withdraw its proposed reductions.

IDF also acknowledges the hundreds of patients and family members from the PIDD community who have contacted their Members of Congress about this critical issue through our online advocacy program, Action Alert. These personal contacts and our patient survey demonstrate that an individual’s input can make a difference on policymaking in Washington.

While this reprieve from reductions is vital to patients with PIDD, IDF does not believe that it goes far enough to bring stability for Medicare beneficiaries. We are taking the same patient survey findings to Congressional Committees and Members of Congress to show them the kinds of dislocations Medicare IVIG users are experiencing as a result of changes in reimbursement policies enacted in 2003. We believe that a permanent adjustment needs to be made in the way Medicare pays for IVIG to assure access to care and choice of provider. Congress may need to take legislative action to make sure this happens.

We celebrate this temporary reprieve for the PIDD community, but recognize that it is not a time to become complacent. IDF urges all of you to again visit our Web site and make your voice heard. Log on to IDF Action Alert at www.primaryimmune.org to contact your Members of Congress and let them know how important access to IVIG is to your health.

IDF Retains Hart Health Strategies

The Immune Deficiency Foundation (IDF) is pleased to announce it has retained the services of Hart Health Strategies. They will work with IDF on legislative and regulatory health issues for patients with primary immune deficiency diseases, and in particular, to restore access to IVIG in all sites of care. Hart Health Strategies focuses exclusively on health care legislation at the Federal level. Each individual at Hart Health Strategies had a distinguished career in the U.S. Congress, serving as senior staff in Congressional Leadership, House/Senate Committees, or the Congressional Research Service. The team that will be working directly with IDF includes: Vicki Hart, President; Sue Ramthun, Principal; Richard Price, Legislative & Health Policy Consultant; and Peter Iovino, Consultant, The Livingston Group.

IDF welcomes Hart Health Strategies and is eager to work together on behalf of the many patients we represent to assure their voice is heard on Capitol Hill and federal government agencies such as the Centers for Medicare and Medicaid Services.
Catch the Spirit of IDF in St. Louis

“It was great, especially helpful to recently diagnosed persons.”

“It was an amazing experience. The IDF is a life saving organization.”

“This was put together just beautifully. I have never felt so relaxed and yet learned a great deal in one weekend.”

These are just a few of the things participants had to say about their experiences at our last national conference in 2005. Plans are currently underway for the 2007 IDF National Conference on June 28-30, 2006 to be held at the Renaissance Grand Hotel, in the heart of St. Louis, Missouri. As the only meeting in the U.S. that brings together members of the primary immune deficient community to learn about these diseases and have the opportunity to discuss and share ideas, it promises to be an event you won’t want to miss!

World-renowned immunologists will share their time and expertise with families. Attendees will learn about scientific advancements in the diagnosis and treatment of the diseases and gain skills needed to manage their health care. Families will have the opportunity to meet other families and talk with the faculty and our generous sponsors in the interactive exhibit hall. And it isn’t all work—fun activities complete with dining and entertainment, are scheduled. We want you to be a part of it!

This year, another benefit has been added—the perfect opportunity to discover the charming city of St. Louis. Rich in history, St. Louis offers something for everyone in this lively metropolis on the Mississippi River. You will be welcomed by the Gateway Arch, where you can take a breathtaking ride to the top and visit the Museum of Westward Expansion below the arch grounds. Explore family attractions like the Saint Louis Zoo, the St. Louis Art Museum, the Missouri Museum of History and the St. Louis Science Center. Riverboat gambling, complete with five casinos to choose from are along the Mississippi. Or take the free tour of the Anheuser-Busch Brewery and you may see the legendary Clydesdale horses.

Our conferences have become a tradition and we expect the 2007 IDF National Conference to be the best yet! Register soon and have the opportunity to “Catch the Spirit of IDF!”
Finding Answers Online
By Linda Keegan

Linda Keegan is an IDF local area volunteer in Madison, Wisconsin, and a member of the IDF Education Committee. Linda received the IDF Volunteer of the Year Award in 2005 for her enthusiastic work and patient advocacy.

If the Internet didn’t exist, I’m not sure I would be here today. I mean that quite literally. I don’t think I would have found the IDF and I’m not sure what my state of health would be without this powerful information tool.

Eight years ago, after being ill for years and losing hope that I would find answers; I had the good fortune to meet a man who changed my life. I was back at the revolving door of my urgent care clinic and telling the physician assistant my medical history. At that time, my symptoms were getting worse. I didn’t just have sinus infections anymore. I had eye and ear infections and asthma. I was plagued with mysterious appearing, disappearing and reappearing scalp outbreaks and lower gastrointestinal discomfort. My childhood had been a series of bouts of infections and the symptoms were coming back in my mid-life. I was ready to seek an herbal remedy, some magical cure, anything. I was just plain weary of medical doctors and their gazes of perplexity. Bottom line, I was frustrated and angry.

After listening to me, this physician assistant said: “There might be something wrong with your immune system.” That day, I came home with a prescription for another round of high-dose antibiotics and the words “immune system” running through my head. I went straight for my computer, and my searches on the Internet were fruitful. I found information about primary immune deficiency. I was ecstatic, yet skeptical. I had already seen a chain of specialists and nobody had ever mentioned anything like “primary immune deficiency”.

However, this comment by the physician assistant inspired me. Along the way, I found IDF and eventually found an immunologist in my home town. I now have a diagnosis and a long-term treatment plan. I feel great now, have been infection-free for years, and continue to learn by going to the Internet daily.

We really are at the cutting-edge of a technology revolution. As healthcare consumers, we have easy access to more information and we are being forced to re-examine our roles in the healthcare process. In no way am I saying that the Internet should replace medical professionals or that we should be disrespectful to highly trained and dedicated doctors and nurses. However, we are in a powerful position to help inspire collaborative relationships, with patients taking more responsibility for managing their chronic illnesses and healthcare professionals listening and learning from their patients. For example, if you find something on the Internet, write down the name and address of the site, print out the information, and bring it to your doctor. Your doctor can help determine whether the information is supported by legitimate research sources, such as journal articles or proceedings from scientific meetings.

Here are a few tips I learned to help you find helpful information to help you cope with a new diagnosis or chronic health condition—

• A good place to start is the IDF site: www.primaryimmune.org
• To help patient and family members navigate the Internet, the Medical Library Association (MLA) offers the “Top Ten” most useful Web sites for health and related information. MLA evaluates Web sites based on the following criteria: credibility, sponsorship/authorship, content, audience, currency, disclosure, purpose, links, design, interactivity, and disclaimers. For the list, go to: http://www.mlanet.org/resources/medspeak/topten.html

Good luck on the Internet…and happy surfing!

A 2006 Pew Internet & American Life Project, “Finding Answers Online in Sickness and in Health” indicates that “as more Americans come online, more rely on the Internet for important health information…. Fully 58% of those [surveyed] who found the Internet to be crucial or important during a loved one’s recent health crisis say the single most important source of information was something they found online.” An earlier Pew report notes that very few healthcare consumers report harmful effects from acting on bad information they found online. See: www.pewinternet.org
IDF Launches Electronic Newsletter

On October 3, 2006, IDF launched the first edition of the Primary Immune Tribune, IDF’s first electronic newsletter. The e-newsletter will provide important disease state and support information for the immune deficient community, and will be delivered on a monthly basis to patients, caregivers, and professionals who comprise the community. Talecris Biotherapeutics is the exclusive supporter of the e-newsletter through a grant to the IDF, allowing the subscription newsletter to be available free of charge to the community.

The Primary Immune Tribune will provide information on a monthly basis that advances IDF’s mission to improve the diagnosis and treatment of patients with primary immune deficiency. Through the newsletter, the primary immune deficient community will receive important, new information about resources, activities, and programs, and will help answer questions and provide quality educational information for patients and their families.

Marcia Boyle, IDF President and Founder, said, “The IDF strives to make sure we provide important information and services for our constituency. The Primary Immune Tribune is an important tool in helping us achieve this goal.”

IS THIS SITE RELIABLE?

As more and more people are turning to the World Wide Web for health related information, the FDA staff and others familiar with Internet medical offerings suggest asking the following questions to help determine the reliability of a Web site:

Who maintains the site?
Government or university-run sites are among the best sources for scientifically sound health and medical information.

Is there an editorial board or another listing of the names and credentials of those responsible for preparing and reviewing the site’s contents?
Can these people be contacted if visitors to the site have questions or want additional information?

Does the site link to other sources of medical information?
A reputable organization will not position itself as the sole source of information on a particular health topic.

When was the site last updated?
Generally, the more current the site, the more likely it is to provide timely material.

Are informative graphics and multimedia files such as video or audio clips available?
Such features can assist in clarifying medical conditions and procedures.

Does the site charge an access fee?
Many reputable sites with health and medical information offer access and materials for free. If a site does charge a fee, be sure that it offers value for the money.

Source: U.S. Food and Drug Administration

For complete document go to:
http://www.fda.gov/fdac/features/596_info.html
### Characteristics of Available Immunoglobulin Products Licensed for Use in the United States - July 2006

<table>
<thead>
<tr>
<th>BRAND NAME</th>
<th>Gammmagard S/D 5%</th>
<th>Gammmagard Liquid</th>
<th>Flebogamma</th>
<th>Octagam</th>
<th>Gamumex</th>
<th>Carimune NF</th>
<th>ZLB Behring</th>
<th>ZLB Behring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manufacturer</td>
<td>Baxter Corporation/ BioScience Division</td>
<td>Baxter Corporation/ BioScience Division</td>
<td>Grifols</td>
<td>Octapharma</td>
<td>Talecris</td>
<td>ZLB Behring</td>
<td>ZLB Behring</td>
<td></td>
</tr>
<tr>
<td>Method of Production (Including Viral Inactivation)</td>
<td>Cohr-Oncley fractionation, ultra-filtration, ion-exchange chromatography, solvent detergent treatment</td>
<td>Cohr-Oncley fractionation, ion-exchange chromatography, solvent detergent treatment</td>
<td>Cold alcohol fractionation, PEG ion-exchange chromatography, pasteurized at 60°C for 10 hours</td>
<td>Cohr-Oncley cold ethanol fractionation, ultra-filtration, chromatography, solvent detergent treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Form</td>
<td>Lyophilized</td>
<td>Liquid</td>
<td>Liquid</td>
<td>Liquid</td>
<td>Lyophilized</td>
<td>Liquid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shelf-Life</td>
<td>24 Months</td>
<td>36 Months</td>
<td>24 Months</td>
<td>24 Months</td>
<td>36 Months</td>
<td>24 Months</td>
<td>24 Months</td>
<td></td>
</tr>
<tr>
<td>Reconstitution Time</td>
<td>&lt;5 minutes at room temperature &gt;20 minutes if cold</td>
<td>None (Liquid Solution)</td>
<td>None (Liquid Solution)</td>
<td>None (Liquid Solution)</td>
<td>None (Liquid Solution)</td>
<td>None (Liquid Solution)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Available Concentrations</td>
<td>5%</td>
<td>10%</td>
<td>5%</td>
<td>5%</td>
<td>10%</td>
<td>3 to 12%</td>
<td>16% (160 mg protein/ml)</td>
<td></td>
</tr>
<tr>
<td>Maximum Recommended Infusion Rate</td>
<td>4 mL/kg/hour</td>
<td>8 mL/kg/hour</td>
<td>5 mL/kg/hour</td>
<td>&lt;4.2 mL/kg/hour</td>
<td>4.8 mL/kg/hour</td>
<td>&gt;2.5 mL/kg/hour</td>
<td>20 mL per hour</td>
<td></td>
</tr>
<tr>
<td>Time to Infuse 35 gms&lt;sup&gt;1&lt;/sup&gt;</td>
<td>2.5 hours</td>
<td>0.6 hours</td>
<td>1 hour</td>
<td>1.6 hours</td>
<td>2.5 hours</td>
<td>1.0 hour</td>
<td>&lt;3.3 hours (6% Solution)</td>
<td>Time will vary depending upon volume &amp; tolerability</td>
</tr>
<tr>
<td>Sugar Content</td>
<td>20 mg/mL glucose</td>
<td>40 mg/mL glucose</td>
<td>No added sugars</td>
<td>50 mg/mL D-sorbitol</td>
<td>100 mg/mL maltose</td>
<td>None</td>
<td>1.67 gm sucrose per gram of protein</td>
<td>None</td>
</tr>
<tr>
<td>Sodium Content</td>
<td>8.5 mg/mL sodium chloride</td>
<td>17 mg/mL sodium chloride</td>
<td>No added sodium</td>
<td>&lt;3.2 mEq/L</td>
<td>&lt;30 mEq/L</td>
<td>Trace Amounts</td>
<td>&lt;20 mg sodium chloride per gram of protein</td>
<td>3 mg/mL</td>
</tr>
<tr>
<td>Osmolarity/Osmolality</td>
<td>636 mOsm/L</td>
<td>1250 mOsm/L</td>
<td>240 - 300 mOsm/kg</td>
<td>310 - 380 mOsm/kg</td>
<td>258 mOsm/kg</td>
<td>192 - 1074 mOsm/kg</td>
<td>445 mOsm/kg</td>
<td></td>
</tr>
<tr>
<td>pH</td>
<td>6.4 - 7.2</td>
<td>4.6 - 5.1</td>
<td>5.9 - 6.0</td>
<td>4.0 - 4.5</td>
<td>6.4 - 6.8</td>
<td>6.4 - 7.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IgA Content</td>
<td>&lt;2.2 µg/mL in a 5% solution</td>
<td>37 µg/mL</td>
<td>&lt;50 µg/mL</td>
<td>&lt;100 µg/mL</td>
<td>46 µg/mL</td>
<td>720 µg/mL</td>
<td>&lt;1700 µg/mL</td>
<td></td>
</tr>
<tr>
<td>Approved Method of Administration</td>
<td>Intravenous</td>
<td>Intravenous</td>
<td>Intravenous</td>
<td>Intravenous</td>
<td>Intravenous</td>
<td>Intravenous</td>
<td>Subcutaneous</td>
<td></td>
</tr>
</tbody>
</table>

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<sup>0.5 gm/kg for a 70 kg adult = 35 gms; 5% Concentrations: Ig = 20 mL; 10% Concentrations: Ig = 10 mL</sup>
<sup>The time to infuse is based on the maximal infusion rate.</sup>
<sup>Check product label for storage temperatures, which vary among Immunoglobulin brands.</sup>
<sup>Check package insert for detailed prescribing information</sup>
<sup>Time will vary depending upon volume & tolerability. Using 35 grams as monthly dose, calculate weekly dose = 8.75 grams = 55 mL infused into 4 sites @ rate up to 20cc/hr/site, which can range from 45 mins. to 3 hrs.</sup>
What Is The Access Program?

ACCESS (Advocating for Chronic Conditions, Entitlements and Social Services) is a program dedicated to helping find solutions to the social and economical problems that confront families facing chronic conditions. The services provided by ACCESS are offered without charge to persons with primary immune deficiencies. ACCESS helps families navigate the often complex maze of state and federal entitlement programs. They also help to explain eligibility for health insurance through state high-risk pools and other alternatives, and through group health insurance continuation under federal law (COBRA and HIPAA). Their goal is to reduce the time and effort required to obtain the benefits you may be entitled to so that you may concentrate your efforts on managing your care and providing for your loved ones.

When to Call ACCESS

Call ACCESS toll free at (888) 700-7010 when any of these apply to you:

- I quit my job
- I lost my job
- I got a new job
- I’m looking for work
- I’m no longer able to work
- I’m about to lose my health insurance
- I’m about to use up my health insurance
- I just lost my health insurance
- I can’t get health insurance
- I just got married
- I just had a child
- I just adopted a child
- My child has lots of medical bills that I can’t pay
- My child just turned 18
- My child is about to leave for college
- My spouse stopped working
- I’m getting a divorce
- I’m moving

Operation Outreach Fall 2006 Meetings

Operation Outreach, the IDF patient education meetings sponsored by ZLB Behring, is in its seventh year and continues to expand. These meetings establish educational opportunities and help develop a network of volunteers and local physicians in all regions of the country. Four successful meetings were held this fall in Long Island, NY, on September 16; Las Vegas, NV, on September 30; Columbus, OH, on October 14; and, Fargo, ND, on October 21.

Presenters at these meetings included: Amanda Cox, MD and Robert Marchlewski, MD of North Shore-Long Island Jewish Health Systems; Lynne Szott, RN, Reimbursement Manager, ZLB Behring; Michael Alazard, MD and Anton Dotson, MD of Aaa-choo Ear, Nose and Throat Specialties of Nevada; David Hauswirth, MD, Ohio State University; Donald McNeil, MD, FAAAAI, Midwest Allergy Associates; Dan Dalan, MD, Allergy and Asthma Care Center; Nathan Kobrinsky, MD, Merit Care Medical Center; Diana Gill, Manager Patient Programs, IDF; and, Kathy Antilla, Director of Education and Volunteer Services, IDF.

The meetings provide attendees with information about resources, a legislative update, an overview of the immune system, treatment options for primary immune deficiency disease, and information regarding health insurance reimbursement.
Online Shopping for Fun and IDF

If you are an online shopper please consider visiting one of these Web sites. These sites will donate a small portion of the purchase price of your order to the Immune Deficiency Foundation. And it doesn’t cost you anything!

These Web sites offer a huge selection of merchandise from well-known companies. IDF is already listed as an approved charity on these Web sites and all you have to do is designate IDF as your charity. A portion of your purchase price, usually from 1% to 5%, will be sent to us.

Go to the Web sites, click on the category of items you are looking for, or the store/company where you want to shop. If you find something you want to purchase, choose the IDF as your designated charity and you will help raise money for the IDF without spending any additional money! It’s as simple as that.

www.charitymalls.com
Each person who registers, as a potential buyer, gets $5 just for signing up and this goes to the charity selected. Signing up is free and easy. Select IDF as your charity and IDF will receive $5 for each registered person, before any purchases are even made!

www.iGive.com
Get an additional $5 contribution for IDF by registering at www.iGive.com and purchasing something within 45 days of joining. The list of participating companies is huge, over 600 stores and includes stores like Barnes and Noble and the GAP. Please be sure to sign up with iGive.com and choose IDF as your charity.

www.MyCause.com
Choose IDF as your selected charity, shop at a retailer affiliated with MyCause and up to 12% of your purchases goes to IDF while you pay nothing extra.

eBay
Are you an eBay junkie? IDF is registered with Mission Fish, a program to help you support IDF through trading on eBay. Mission Fish permits sellers to donate a percentage of the profit they make from items they sell on eBay. Visit www.ebay.com/givingworks to get started. In addition, buyers may designate IDF as a charity to receive 1.6% of sales by registering first with www.iGive.com before buying any items on eBay auctions. eBay sellers can designate all or a portion of their listings to go to IDF.

Shopping online can be a fun and convenient way to shop — and now it can be a valuable source of income for IDF all year long. Please spread the word to anyone you know who might shop online. Happy shopping and thanks for your support!

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.

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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
Sonia Green, IDF Volunteer and mother of three boys with XLA, notified us that her friend and co-worker Maureen Straub Kordesh (pictured end right) recently raised funds for IDF during a voice recital. Sonia used this opportunity to distribute information about primary immune deficiency diseases and talk to people about the diseases at the recital.

The Immune Deficiency Foundation and The Goldie Hawn Institute had a ball on Friday, October 27 in Minneapolis, MN. IDF has been selected as one of the Goldie Hawn Institute’s partner organizations. The event included a silent and live auction, a fashion show, live music, and wining and dining. Pictured from L to R are IDF Planning Committee members: Elizabeth Hart, Cathy Hart, Kathy Antilla, Heidi Jensen, Shelly Doll and Joan Schwarz. Also pictured is Dr. Fred Goldman from the University of Iowa Pediatric Immunology Department, and Goldie Hawn, in the middle.
Champions Circle of Support 2007

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The Champions Circle 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.

Visit our Web site for updates
www.primaryimmune.org/conferences/conf_2007.htm