Set Sail for a Healthier Life

This June, the Set Sail for a Healthier Life Family Retreat at beautiful Wintergreen Resort in Virginia offered a wonderful opportunity for patients, families, children, physicians and industry representatives from the immune deficiency community to learn more about primary immune deficiencies, share experiences and have fun at the same time. Adult sessions offered new information from knowledgeable speakers while the youth programs were packed with fun-filled learning for all ages. Everyone had the opportunity to become acquainted with others to share ideas, offer support and learn from each other.

Many thanks to our presenters including: Marcia Boyle, President & Founder of the IDF; Richard Schiff, MD, PhD, Global Director for Immune Therapy for Baxter BioScience, Baxter Healthcare Corporation; Lisa Filipovich, MD, Medical Director, Hematology/Oncology Diagnostic Laboratory at Cincinnati Children’s Hospital Medical Center; Wei Zhao, MD, PhD, Pediatrics: Allergy, Immunology & Rheumatology at Virginia Commonwealth University Health System; Michelle Vogel, Partner of Washington Strategic Consulting; Terry Harville, MD, PhD, Associate Professor of Pathology at the University of Arkansas for Medical Sciences; Maggie Coyne, RN, CPNP at Baylor College of Medicine; and, Lynne Szott, RN, Manager of Reimbursement for Immunoglobulin Products at ZLB Behring.

Special thanks to Gail Moore, IDF volunteer and Retreat Director extraordinaire, along with her team of helpers. Gail has been leading IDF family retreats since 1997 and each year they continue to get better. If you weren’t able to attend this June retreat, there is a second chance to Set Sail for a Healthier Life at the Family Retreat at the Glen Eyrie Conference Center in Colorado on November 17-19. Call IDF at 800.296.4433 for more information. These retreats are generously supported by Baxter Healthcare Corporation, Grifols, NuFactor, Talecris Biotherapeutics and ZLB Behring.
We Need Your E-mail Address

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

E-mail us at idf@primaryimmune.org,
Phone us at 800.296.4433 or 410.321.6647

Register for IDF Action Alert

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

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

IDF Advocate

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David’s Life of Courage, Patience and Understanding

Public Broadcasting Services (PBS) recently showed a television documentary, “The Boy in the Bubble” about David Vetter. David was afflicted with a rare hereditary disease, severe combined immunodeficiency (SCID) and spent his entire twelve years of life inside a sterile isolator, referred to as the “bubble.”

At the time of his birth in 1971, a bone marrow transplant from an exact matched donor was the only cure for SCID, but there was no match available in David’s family. The bubble was considered a form of treatment. With his better interest in mind, David’s family proceeded with this, then innovative and medically advanced therapy, to keep their baby healthy.

Carol Ann Demaret, David’s mother, a member of the IDF’s Board of Trustees and a valued volunteer for the IDF patient community for more than 15 years, recently spoke with us about the PBS program. While Carol Ann does not agree with some of the perspectives in the program, she is thankful that the program generated interest about SCID and hopes that it might transfer into more funding for research to benefit all people affected by primary immune deficiency diseases.

Speaking for her family, including David’s father and sister, Carol Ann said, “As parents of an afflicted child, the only thing we had in our control was to see that David received the best possible care. We trusted our doctors. We were grateful for the bubble; the bubble was the only treatment option available for David at the time. If it hadn’t been for the bubble, we would not have had him for 12 years. Our goals were to keep David safe, bring the outside in and make sure he felt loved.”

“David’s life showed courage, patience and understanding. He accepted the unique circumstances of his life, but waited to find the way to come out of his bubble. We prepared him to be able to socialize and eventually join the outside world. Science was protecting David, this was never an experiment.”

Carol Ann wishes the program had not just concentrated on his existence, but showed more about David as a person and further discussed SCID and its devastating affects. David had friends, was schooled at home and the hospital by teachers, and played and fought with his sister just like any little brother. He was involved in all aspects of their home life. She fondly remembers Halloweens when David, dressed in a costume in the bubble, handed candy out to other trick-or-treaters through the rubber gloves.

They were careful to keep him away from the attention in the media, but once when he was eight or nine, David saw his picture in the newspaper.

“The next day, he told me that he was a star. I didn’t know what he was referring to and told him that, yes indeed he was a star because he lights up my life. David quickly corrected me and told me that he was a star because his picture was in the paper the day before and stars don’t have to clean up toys. I told him that his picture wasn’t in the paper today, so today you clean up your bubble!” Carol Ann lovingly remembers.

Carol Ann believes, and science has stated, that because of what was learned from David’s gallant life and death, many children with SCID have since been diagnosed early, received bone marrow transplants and now lead healthy lives. In Carol Ann’s words, “David was a great blessing to our family and to the world.”
Infants with Severe Combined Immunodeficiency Disease (SCID) have the most serious of the primary immunodeficiency diseases, with little or no immune system. They die from infection before their first or second birthday if not given immune reconstitution by bone marrow transplantation. SCID is a pediatric emergency.

If a SCID baby receives a bone marrow transplant in the first 3.5 months of life, the survival rate can be as high as 95 percent. However, the survival rate drops to 71 percent for infants who are transplanted after that age. The main causes for the drop in survival rate are serious infections SCID babies develop in the first few months of life. The condition can be detected at birth; however, it is currently not among the genetic diseases routinely tested for in newborn screening. For most SCID infants, the diagnosis is not made until 6.5 months of age on average, and most patients are critically ill by then. Twelve molecular forms of SCID have been identified in the past 13 years, caused by mutations of single genes. The most common form of SCID is X-linked recessive, a mutation inherited on the X chromosome. This form of SCID affects only boys, but accounts for 46 percent of U.S. cases.

Rebecca H. Buckley, MD, Chairperson of the IDF Medical Advisory Committee has been a major advocate for the past 10 years for screening for SCID at birth. A Professor of Pediatrics and Immunology at Duke University Medical Center in Durham, North Carolina, Dr. Buckley commented on her experiences.

“My colleagues at Duke University Medical Center and I treat SCID patients via stem cell transplants derived from donor bone marrow, typically from a parent or matched sibling. Of the 156 SCID patients I have treated at Duke, 122 (78 percent) are alive. Most are in good general health. The oldest is 24 years of age. All 16 recipients of marrow from perfectly matched donors and 106 of the 140 recipients of T cell-depleted marrow from parental donors are among the survivors. Twenty-seven of the 34 deaths occurred from viral infections present at the time of diagnosis.”

“Of the 44 infants I have transplanted during the first 3.5 months of life, all but two (95 percent) survived, compared to 80 survivors among the 112 transplanted after that age (71 percent survival). SCID patients who receive stem cell transplants within the first 28 days of life develop earlier and more robust immune function than do those who receive transplants later, with higher levels of T cell reconstitution and output from the thymus gland.”

Early treatment not only saves lives but also reduces costs. For example, a bone marrow transplant performed in a SCID infant in the first three months of life can cost less than $60,000, but the cost of care skyrockets up to millions of dollars in older SCID patients, primarily for treatment of their life-threatening infections, with less assurance of success.

“I cannot begin to stress enough the importance of early diagnosis and newborn screening for immunodeficiency diseases. While technology has not been developed to screen newborns for all primary immunodeficiencies, it has been developed for the most severe form, SCID. There are several types of screening tests that could be used, one already available and others which are under evaluation. Dr. Jennifer Puck at the National Human Genome Research Institute has developed one type of test that could be used to test newborns for SCID. Without an effective early intervention, the majority of SCID babies die during the first year of life,” Dr. Buckley warned.

IDF believes that now since the technology has been developed, a pilot study should be done to begin screening all newborns for SCID at birth. IDF is currently seeking Congressional support to create a newborn screening pilot program for Severe Combined Immunodeficiency Disorders.

For additional information on Newborn Screening, please call Christine Belser, Senior Director of Programs & Communications at 800.296.4433.
Marcia Boyle, President & Founder of IDF, testified at the hearing on the impact of Medicare reimbursement of physician-administered drugs on patients on July 13, 2006 in Washington D.C. Congresswoman Nancy L. Johnson (R-CT), Chairwoman of the House Ways and Means Subcommittee on Health, called the meeting to focus on implementation of the revised payment methodology for reimbursement of physician-administered drugs, which includes Intravenous Immunoglobulin (IVIG), and examine the effects of this new payment system on providers and beneficiaries.

Marcia Boyle joined the two panels of witnesses that included Herb B. Kuhn, Director, Center for Medicare Management at the U.S. Department of Health and Human Services; Robert A. Vito, Regional Inspector General for Evaluations and Inspections, U.S. Department of Health and Human Services; Mark Miller, PhD, Executive Director, Medicare Payment Advisory Commission; Bruce Steinwald, Director, Health Care, Economic and Payment Issues, U.S. Government Accountability Office; Frederick M. Schnell, MD, President, Community Oncology Alliance; Joseph S. Bailes, MD, Executive Vice President, American Society of Clinical Oncology; Richard Friedman, Executive Chairman, Bioscrip; and Jordan S. Orange, MD, PhD, Chair, Primary Immunodeficiency Disease Committee, American Academy of Allergy, Asthma and Immunology.

Marcia spoke on behalf of the more than 50,000 immune deficient patients, as well as all other patients across America who need IVIG as their lifesaving therapy. She described the plight of patients not having access to IVIG as a nightmare and relayed the accounts of thousands of patients and physicians who could no longer receive or administer IVIG because of the reduced Medicare rates. Marcia stressed that the impact of Medicare doesn’t stop with Medicare patients. In recent months, IDF has heard of many private insurance carriers reducing their rates to match Medicare, endangering even the lives of children.

She recounted the testimony of Pam Way, one of the patients who testified at the U.S. Department of Health and Human Services (HHS) on Blood Safety and Availability Advisory Committee in May of 2005. Pam had lost access to IVIG when the Medicare Modernization Act (MMA) was implemented. She was forced to be transitioned from her physician’s office to a hospital where she could no longer receive the brand of IVIG she needed, at the frequency required to maintain her health. Pam literally begged for her life, but sadly, died as a result of the lack of continuity of treatment she needed.

“It is a national disgrace that this problem has persisted for more than a year and a half and nothing has been done to restore access to IVIG. I implore the Subcommittee to take emergency action today to restore access to IVIG in all sites of care. End the nightmare that has devastated our community!” Marcia stated.

Reps. McCrery and Foley passionately stressed the need to immediately restore access for patients who rely on IVIG. Both explained to the federal agencies that patients can not continue to go without their treatment or they will die.

Congressman McCrery thanked Marcia Boyle for the leadership role IDF has taken on the access to IVIG issues. He said that without the efforts and work of IDF, Congress would not understand the level of devastation that has occurred for this community. He and Chairwoman Johnson both assured Marcia that they are committed to restoring access for our community.

IDF is committed to continuing its efforts to restore patient access to IVIG therapy and urges you to assist in the campaign. Please visit www.primaryimmune.org and participate in the IDF Action Alert. Please share your personal stories with your Members of Congress, and if your Representatives have not supported this effort, please ask them to join in restoring access to IVIG by contacting Secretary Leavitt immediately.

Marcia Boyle and Jordan Orange, MD, PhD, a member of IDF Medical Advisory Committee, testify at the hearing.

**LEGISLATIVE WIN!**

We are happy to report that Enzi Bill, S. 1955, was defeated in a 55-43 vote on May 11, 2006. The Immune Deficiency Foundation worked with other health community organizations to convince members of congress that this amendment would have hurt more Americans than help them. The legislation was designed to make health insurance more widely available for employees working at small businesses. Unfortunately, this legislation may have also been harmful to individuals with high cost chronic conditions and had the potential to restrict access to life-saving therapies, such as IGIV. We are happy to have been a part of this win.
Insurance Issues

Question: Are you having problems with your IGIV claims being reimbursed through your private insurance carrier?

CONSIDER: Did your provider submit the claim to the insurance company with the new billing codes for 2006?

<table>
<thead>
<tr>
<th>New HCPCS Code</th>
<th>Description</th>
<th>Unit of Measure</th>
<th>Replaced HCPCS Code</th>
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</thead>
<tbody>
<tr>
<td>J1566</td>
<td>Injection, immune globulin, intravenous, lyophilized</td>
<td>500 mg</td>
<td>Q9941 - 1 gram</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Q9942 - 10 mg</td>
</tr>
<tr>
<td>J1567</td>
<td>Injection, immune globulin, intravenous, non-lyophilized</td>
<td>500 mg</td>
<td>Q9943 - 1 gram</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Q9944 - 10 mg</td>
</tr>
<tr>
<td>G0332</td>
<td>Pre-administration</td>
<td>NA</td>
<td>Does not replace any existing HCPCS Code</td>
</tr>
</tbody>
</table>

Question: Does your hospital have a priority list for IGIV, and you are not on it?

CONSIDER: Ask questions about what diagnoses come before yours. The challenge is finding the right person at the hospital to assist you. For example, one patient shared his experience, “I did end up talking to the right person at the hospital. I talked with their head of quality assurance and told them my story. They were surprised and I requested an investigation into their reasoning behind the monthly waiting list for IGIV. They talked with their head pharmacist and officially I’m no longer on their waiting list and they will now comply with my standing monthly order for IGIV.”

Immune Deficiency Foundation Event Calendar*

August 17, 2006
5:00-9:00 pm
Arizona Patient Meeting
Windmill Suites at St. Phillips Plaza
4250 N. Campbell Ave.
Tucson, AZ 85718
Register by calling IDF at 800.296.4433
Contact Sonya Vohnout at 520.270.2654 or e-mail vohnout1@comcast.net

September 5-6, 2006
LeBien Visiting Professor Program
Advocate Hope Children’s Hospital, Oak Lawn, IL
Visiting Professor; Dr. Rebecca H. Buckley
Contact Tamara Brown at 410.321.6647

September 20-12, 2006
LeBien Visiting Professor Program
Children’s Medical Center at Dallas, Dallas, TX
Visiting Professor; Dr. Hans Ochs
Contact Tamara Brown at 410.321.6647

Fall 2006
LeBien Visiting Professor Program
St. Joseph’s Children's Hospital and Medical Center, Phoenix, AZ
Visiting Professor; TBA
Contact Tamara Brown at 410.321.6647

October 7-10, 2006
American Academy of Pediatrics 2006 National Conference
Atlanta, GA

October 18-19, 2006
LeBien Visiting Professor Program
Children’s Mercy Hospitals & Clinic, Kansas City, MO
Visiting Professor; Rebecca H. Buckley, MD
Contact Tamara Brown at 410.321.6647

November 17-19
IDF Family Retreats 2006
“Set Sail for a Healthier Life”
Glen Eyrie Conference Center
Colorado Springs, Colorado
Call the Family Retreat Line at 866-709-9499 or e-mail idfretreats@verizon.net

November 27-28, 2006
LeBien Visiting Professor Program
University of Arizona, Tucson, AZ
Visiting Professor: Erwin Gelfand, MD
Contact Tamara Brown at 410.321.6647

November 10-15, 2006
American College of Asthma Allergy & Immunology 2006 National Conference
Philadelphia, PA

*Updated July 25, 2006
Armed with the determination and personal resolve that they had an important story to tell, over 60 IDF volunteers climbed the steps to our nation’s Capitol. Their mission was to meet with their Members of Congress to share information about primary immune deficiency diseases. They wanted to alert their legislators about the current Medicare reimbursement rates for intravenous immune globulin (IVIG). They were alarmed because the cost for IVIG exceeds the current reimbursement payment from the Centers for Medicare and Medicaid Services (CMS) and this is preventing health care providers from purchasing and administering IVIG. And, they wanted to discuss IDF’s efforts to develop a federal program to screen all newborn babies for severe combined immune deficiency (SCID).

That is just what the volunteers did! A total of 144 meetings took place and 110 Members of Congress were reached. Our volunteers’ personal stories and experiences with primary immune deficiency diseases were invaluable in helping Members of Congress understand the importance of supporting initiatives for improved reimbursement rates for immune globulin therapies and support for newborn screening.

IDF volunteers did an excellent job of explaining to their Members of Congress that:

- Most patients with primary immune deficiency diseases have compromised immune systems and cannot go without their IVIG.
- Most patients with primary immune deficiency diseases react differently to each brand of IVIG, and therefore need access to all brands.
- Most patients with primary immune deficiency disease are particularly vulnerable to the many infections to which individuals in a hospital are exposed.
- Reimbursement should never dictate if a patient receives their lifesaving therapy, where a patient receives lifesaving therapy, and when a patient receives their lifesaving therapy.

Finally, the volunteers urged their Members of Congress to raise newborn screening as a federal goal. IDF is requesting $900,000 in Federal Support in Fiscal Year 2007 to create a newborn screening pilot program for Severe Combined Immunodeficiency Disorders. The diagnosis of this condition very early in life is a true pediatric emergency.

As a result of IDF Capitol Hill Day, there has been heightened interest among Members of Congress to find a solution to the IVIG crisis. Through IDF efforts, three members of the House of Representatives, Rep. Jim McCrery (R-LA), Rep. Mark Foley (R-FL), and Rep. Steve Israel (D-NY), have taken the lead to develop a letter from Congress to The Honorable Michael Leavitt, Secretary of the Department of Health and Human Services. The letter details the current state of the IVIG crisis and asks Secretary Leavitt to declare a public health emergency regarding access to IVIG. Declaring a public health emergency provides the CMS with the authority to adjust the reimbursement for IVIG on a short-term basis.

IDF appreciates the American Academy of Allergy, Asthma and Immunology, Baxter Healthcare Corporation, Grifols, NuFactor; Talecris Biotherapeutics and ZLB Behring for sponsorship of IDF Capitol Hill Day. Special thanks are also extended to Baxter Healthcare Corporation, NuFactor and Talecris Biotherapeutics for supporting our Grassroots Educational Program.

During the Capitol Hill day breakfast ceremony, IDF awarded three Members of the House with the Distinguished Public Policy Award for leading the charge to fix the IVIG access problem.

(L to R) Mark Stein, MD, and Lynne Szott, Manager of Reimbursement for Immunoglobulin Products from ZLB Behring, present the award to Rep. Mark Foley (R-FL)

(L to R) Carol Ann Demaret, IDF Board Member, and Mark Davis-Lorton, MD, present the award to Rep. Steve Israel (D-NY)
Update: Reps. McCrery, Foley, Israel and 55 Members of the House of Representatives send a letter to HHS Sec. Leavitt to restore access to IVIG!

Fifty-five Members of the House of Representatives have signed onto the McCrery/Foley/Israel letter to Health and Human Services Secretary Leavitt, asking him to declare a public health emergency, so that patient access to IVIG can be restored immediately. Special thanks are extended to the staff of these Representatives who made this campaign possible: Laura Bozell from Rep. McCrery’s office, Bradley Schreiber from Rep. Foley’s office and Meghan Dubyak from Rep. Israel’s office.

SPECIAL THANKS

House Representatives for their continued support to restore access to IVIG

Rep. Xavier Becerra (D-CA)
Rep. Michael Burgess (R-TX)
Rep. Michael Bilirakis (R-FL)
Rep. Henry Bonilla (R-PA)
Rep. Mary Bono (R-CA)
Rep. Henry Brown (R-SC)
Rep. Michael Burgess (R-CA)
Rep. Michael Ferguson (R-NJ)
Rep. Bob Filner (D-CA)
Rep. Mike Fitzpatrick (R-PA)
Rep. Virgil Goode (R-VA)
Rep. Kay Granger (R-TX)
Rep. Alcee Hastings (D-FL)
Rep. John Ramstad (R-MN)
Rep. Cliff Stearns (R-FL)
Rep. John Tanner (D-TN)
Rep. William Jefferson (D-LA)
Rep. Nancy Johnson (R-CT)
Rep. Sam Johnson (R-TX)
Rep. Sue Kelly (R-NY)
Rep. Tom Latham (R-IA)
Rep. Frank LoBiondo (R-NJ)
Rep. Nita Lowey (D-NY)
Rep. Thaddeus G. McCotter (R-MI)
Rep. Joe Myers (R-NC)
Rep. Charlie Norwood (R-GA)
Rep. C.L. “Butch” Otter (R-ID)

House Representatives for supporting the public health emergency campaign to Restore IVIG Access Immediately

Rep. Gary Ackerman (D-NY)
Rep. Tammy Baldwin (D-WI)
Rep. Howard Berman (D-CA)
Rep. Tim Bishop (D-NY)
Rep. Rob Bishop (R-UT)
Rep. John Boozman (R-AR)
Rep. Kevin Brady (R-TX)
Rep. Sherrod Brown (D-OH)
Rep. Jim Campbell (D-MI)
Del. Donna Christenson (D-VI)
Rep. John Conyers, Jr. (D-MI)
Rep. Jo Ann Davis (R-VA)
Rep. Peter DeFazio (D-OR)
Rep. Eliot Engel (D-NY)
Rep. Phil English (R-PA)
Rep. Anna Eshoo (D-CA)
Rep. Sam Farr (D-CA)
Rep. Michael Fitzpatrick (R-PA)
Rep. Mark Foley (R-FL)
Rep. Barney Frank (D-MA)
Rep. Gene Green (D-TX)
Rep. Paul Grijalva (D-AZ)
Rep. J.D. Hayworth (R-AZ)
Rep. Brian Higgins (D-NY)
Rep. Maurice Hinchey (D-NY)
Rep. Michael Honda (D-CA)
Rep. Steve Israel (D-NY)
Rep. Dale Kildee (D-MI)
Rep. Dennis Kucinich (D-OH)
Rep. Rick Larsen (D-WA)
Rep. Carolyn Maloney (D-NY)
Rep. Carolyn McCarthy (D-NY)
Rep. Jim McCrery (R-LA)
Rep. Michael McNulty (D-NY)
Rep. Gregory Meeks (D-NY)
Rep. Shelley Moore Capito (R-WV)
Rep. Dennis Moore (D-KS)
Rep. Jim Moran (D-VA)
Rep. James Oberstar (D-MN)
Rep. Frank Pallone (D-NJ)
Rep. Ron Paul (R-TX)
Rep. Jim Ramstad (R-MN)
Rep. Charlie Rangel (D-NY)
Rep. Silvestre Reyes (D-TX)
Rep. Bernard Sanders (I-VT)
Rep. Adam Schiff (D-CA)
Rep. Clay Schuette (R-MI)
Rep. Chris Shays (R-CT)
Rep. Don Shelly (D-NE)
Rep. James Walsh (R-NY)
Rep. Robert Wexler (D-FL)
Rep. Bill Young (R-FL)
Rep. Chip Pickering (R-MS)
Rep. Joseph Pitts (R-PA)
Rep. Todd Akin (R-MO)
Rep. Silvestre Reyes (D-TX)
Rep. Steve Rothman (D-NJ)
Rep. Jim Saxton (R-NJ)
Rep. Pete Sessions (R-TX)
Rep. John Shinkus (R-IL)
Rep. Ike Skelton (D-MO)
Rep. Hilda Solis (D-CA)
Rep. Cliff Stearns (R-FL)
Rep. John Sullivan (R-OH)
Rep. Anthony Weiner (D-NY)
Rep. Jerry Weller (R-LA)
Staff of the House Energy and Commerce Committee
Staff of the House Ways and Means Committee

Capitol Hill Day Volunteers at the training session.
Strengthening Our Roots -- 2006 Volunteer Leadership Conference

Strengthening Our Roots, this year’s IDF Volunteer Leadership Conference, offered over 70 volunteers from all over the country the opportunity to get down to basics. The volunteers learned new medical information while developing their communication skills and sharing ideas with each other.

This leadership conference emphasized the importance of IDF Peer Support Volunteers—these volunteers are often the first people newly diagnosed patients with primary immune deficiency diseases can truly share their feelings. So often, patients living with primary immune deficiency diseases feel isolated; they don’t know anyone who has their disease and nobody seems to understand their situation. When a patient calls the IDF office asking for support, arrangements are made for a Peer Support Volunteer to contact the patient or family member and lend support. Sometimes, patients are connected with volunteers in their own state, or attempts are made to find someone with the same diagnosis or age. Every effort is made by IDF to make this critical connection helpful and compassionate.

The conference began with a welcome from Larry Guiheen, President of Baxter’s BioScience business in the United States. Larry represented this year’s conference sponsor, Baxter Healthcare Corporation. He emphasized the vital role IDF volunteers play in the lives of people living with primary immune deficiency diseases.

“Baxter believes that the Immune Deficiency Foundation and its volunteers do a remarkable job in assisting patients and their families with immune disorders. We are pleased to support the 2006 Volunteer Leadership Conference and facilitate the gathering of volunteers to come together to discuss a range of issues, including primary immune deficiency diseases, state-of-the-art pathogen safety, advocacy, and peer support.” Larry Guiheen declared.

He also invited the volunteers to tour the Baxter manufacturing facility in Glendale, California the next day. It was an incredible opportunity for volunteers to go behind the

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**IDF Volunteer Opportunities**

*Interested in working with IDF? There are many opportunities to use your time and talents to make a difference. IDF knows your time is valuable and offers flexible options for even the busiest people. Check out the possibilities:*

**Peer Support Volunteers** must be either patients or immediate family members and have at least a 2 year diagnosis of a primary immune deficiency disease. Volunteers trained to provide peer support to patients and family members, and coordinate patient education meetings in their state. Currently, there are 113 Peer Support Volunteers in 37 states.

**Fundraising Volunteers** are involved in coordinating local fundraising special events, including participating in the Blue Jeans for Healthy Genes Program.

**Grassroots Advocacy Volunteers** are trained as effective advocates to engage in federal and state legislative issues. They are part of a legislative action group network of volunteers to represent as many states and congressional districts as possible. Volunteers also distribute media alerts and timely stories locally to media and recruit other volunteers to become involved.

If you are interested in becoming a volunteer, please contact Kathy Antilla, Director of Education & Volunteer Services at 800.296.4433.
Successful Operation Outreach

Operation Outreach, the IDF patient education meetings sponsored by ZLB Behring, is in its 7th 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.

Two Operation Outreach meetings have been held and four more are scheduled for this fall. In March at the Franklin Institute Science Museum in Philadelphia, 87 patient and family members met to learn more about primary immune deficiency diseases. Marcia Boyle, President & Founder of IDF, spoke about the activities of IDF and Jordan Orange, MD, PhD and Kathleen Sullivan, MD, PhD from The Children’s Hospital of Philadelphia, presented information on the immune system and therapeutic approaches to primary immune deficiency diseases. Lynne Szott from ZLB Behring, tried to demystify insurance issues and Michelle Vogel and Julie Pawelczyk from Washington Strategic Consulting, gave an update on public policy and the importance of everyone’s involvement in grassroots advocacy.

At the Little Rock, Arkansas Statehouse Convention Center in April, 70 members of the primary immune deficient community met. Faculty from Arkansas Children’s Hospital and the University of Arkansas for Medical Sciences were the presenters. Tamara Perry, MD, Stacie Jones, MD, Amy Scurlock, MD and Terry Harville, MD, PhD discussed diagnosis, treatment, manifestations and complications of primary immune deficiencies. Lynne Szott and Michelle Vogel also presented.

Four more Operation Outreach meetings are planned for this fall. For information, contact Diana Gill, Patient Services Manager at 800.296.4433.

 Calling all Doctors!

Give your patients the benefit of a second medical opinion on primary immune deficiency diseases from a national network of renowned immunologists. The IDF Consulting Immunologist Program offers:
- Free physician to physician consults
- Consults or second opinions on issues of diagnosis, treatment and disease management
- Access to faculty of recognized leaders in clinical immunology

Simply call 877.666.0866 to request a consult.

Provide your faculty with a Visiting Professor with expertise in primary immune deficiency diseases. Consider the benefits of our LeBien Visiting Professor Program:
- Available to teaching hospitals throughout North America
- Expert clinical immunologists to lead grand rounds and other educational activities
- Increases knowledge of the diagnosis and treatment of primary immune deficiency diseases

For more information, contact Tamara Brown, Director of Medical Programs at 800.296.4433 or e-mail tb@primaryimmune.org.
Hanging Up Blue Jeans!

Blue Jeans are hanging up all over BioLife Plasma Services Centers in Minnesota, North Dakota, Wyoming and Arkansas. BioLife Centers in these states hosted IDF Blue Jeans for Healthy Genes in April and the response was incredible. At the IDF Minnesota Family Conference Day in May, Melaine Zeigler and Joan Schwarz, IDF Volunteers, happily accept a check for $8,700 from Kathy Hagen and Amy Boyer from BioLife.

BioLife Plasma Services Centers collect plasma that is processed into life-saving plasma-based therapies that are infused by patients with antibody deficiencies. BioLife operates over 50 plasma collection facilities throughout the United States and collects nearly 3 million liters of plasma per year. By the end of the summer, all of these centers will have participated in the Blue Jeans for Healthy Genes Program. BioLife has generously agreed to match the funds raised in the centers up to $50,000.

During the Blue Jeans for Healthy Genes programs, patients and family members who infuse with immunoglobulin will be invited to the centers to share their stories with donors and staff and “put a face on primary immune deficiency disease.” Visiting the centers is a great way to create awareness of primary immune deficiency diseases and to thank the donors and staff who are the first step in the plasma collection process.

A Sweet Lesson

IDF board member, Barb Ballard, included a creative genetics lesson at her son’s school in Fairfax County, Virginia, as part of their Blue Jeans for Healthy Genes Night.

First, Barb gave each student 2 twizzlers, 10 jelly beans and 5 toothpicks and each child built a model of DNA. Then each student exchanged 1 jelly bean with another student for a jelly bean of a different color and reassembled their DNA. This represented a change or mutation in this particular DNA strand. The exercise gave the children a concrete picture in their minds and set the stage for Barb’s power point lesson explaining DNA and what genes do.

A Sweet Lesson

IDF board member, Barb Ballard, included a creative genetics lesson at her son’s school in Fairfax County, Virginia, as part of their Blue Jeans for Healthy Genes Night.

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Victoria, Lisa and Tom Russo enjoyed a beautiful day on the slopes at the 1st Annual Burst the Bubble Ski-a-thon at Windham Mountain in New York in February 2006. Forty skiers participated and over $10,000 was raised through pledges, sponsors, raffles and t-shirt sales. Congratulations to the Russo Family for organizing this successful event. They credited their success on the help and generosity of family, friends and the ski resort, and they have already scheduled the 2nd Annual Ski-a-thon for the last Saturday in February 2007 at Windham Mountain.

Smiles were all around when representatives of ZLB Behring, Dennis Jackman, Senior Vice President Public Affairs; Gene Kotz, R. PhD, Sr. Director Marketing Critical Care and Immunology; and, Bernadine Dixon, Associate Director-Ig Product Marketing; presented Marcia Boyle, President & Founder of IDF with a check for their Blue Jeans for Healthy Genes activities. This is the third year ZLB Behring has participated in this IDF signature fundraising and awareness program.
With Gratitude
The Immune Deficiency Foundation gratefully acknowledges those who generously contribute to the Foundation to celebrate the memory of someone who has died or to honor someone special.

Gifts In Memory Of
Joe Altomare
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Kathy & Larry Whittle

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. Or you can contact us in any of the following ways:

Phone: 800.296.4433 or 410.321.6647
E-mail: idf@primaryimmune.org

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E-mail: idf@primaryimmune.org

Mail:
IDF
40 W. Chesapeake Avenue
Suite 308
Towson, MD 21204

Combined Federated Campaign #9808

Kudos to these organizations for hosting Blue Jeans for Healthy Genes!

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Target Disc Center
Target Stores
The SMS Group
T. L. Carey, MD
ZLB Behring

The walls at Talecris Biotherapeutics were covered with jeans! All of the sites of Talecris Biotherapeutics joined together to “hang up jeans” to make their Blue Jeans for Healthy Genes project a great success.
Circle of Support

Baxter Healthcare Corporation
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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.