Immune Deficiency Foundation Celebrates Silver Anniversary and a Legacy of Firsts in 2005

The Immune Deficiency Foundation will celebrate its 25th anniversary in 2005. Our 25th anniversary theme, “A Legacy of Firsts,” provides a unique opportunity to reflect on the tremendous progress our community has made in advancing the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy. It also provides the means to launch important new initiatives that will continue IDF’s leadership well into the future.

2005 is the year in which we will strengthen our organization, expand our grassroots volunteers and our services and support for individuals and families. We will build upon our strong commitment to our core programs and services for the patient and medical communities, as well as launch new initiatives.

Together with you, IDF plans to:

• Release the first diagnostic and clinical care guidelines for primary immune deficiency diseases and empower physicians, health care providers, patients and family members to use these guidelines as a tool for diagnosis, treatment and advocacy;

Medicare Reimbursement for IGIV May Shift Patients to Hospitals

As of January 1, 2005, the Centers for Medicare and Medicaid Services (CMS) will be changing the reimbursement methodology for intravenous immune globulin (IGIV) provided by physicians in their offices, infusion suites and home care settings from average wholesale price (AWP) to average sales price (ASP). Payments to non-hospital providers will decrease from the 2004 rate of $66 per gram under Medicare to $40 per gram. Since providers may not be able to purchase IGIV at $40 per gram, patients may be sent to hospitals to receive their infusions where IGIV is being reimbursed at $80 per gram.

The Immune Deficiency Foundation (IDF) has been working with CMS and key Members of Congress to increase the reimbursement for IGIV. IDF advo-
A MESSAGE FROM THE EDITOR

I hope you enjoy this issue of the IDF Advocate. The Winter 2004 national newsletter highlights IDF’s Legacy of Firsts and the dedication of volunteers across the country.

I am extremely proud to be a part of the IDF community and I have enjoyed working with all of you to improve the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy.

Briana Cassidy

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• Expand our national grass roots policy network focusing on primary immune deficiency diseases. The first task for this network is urgent: to ensure access to life-saving IGIV therapy through adequate reimbursement in all sites of service;

• Educate the community about scientific advancements in the diagnosis and treatment of primary immune deficiency diseases and empower individuals to gain the skills and support needed to participate in the management of their health care at the Third IDF National Conference in June 2005;

• Provide local peer support and educational opportunities for individuals and families through our Volunteer Support Network;

• Increase awareness of primary immune deficiency diseases among health professionals through the Visiting Professor Program and Consulting Immunologist Hotline;

• Enhance earlier diagnosis of primary immune deficiency diseases by facilitating the development of newborn screening; and

• Accelerate medical discoveries that will lead to improved patient care through the USIDNET and advocacy.

IDF, more than ever, is committed to enhancing our leadership for individuals and families affected by primary immune deficiency diseases, as well as the medical community. Thank you for being a part of the Immune Deficiency Foundation. We look forward to celebrating IDF’s silver anniversary and our “Legacy of Firsts” with you throughout the upcoming year.

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cates that physicians and patients should decide what site of service is best based on clinical appropriateness and individual circumstances, and reimbursement should never dictate where a patient receives an IGIV infusion. Different sites of service should be available to patients and all should receive equal and adequate reimbursement.

In the Medicare Modernization Act (MMA), Congress exempted IGIV from competitive bidding, giving patients access to all brands of IGIV. Additionally, Congress added a new site of service for primary immune deficient patients to receive IGIV, the home care setting. However, with the new rates being proposed by CMS, patients risk losing access to all products and most sites of service. Any patients having problems receiving IGIV infusions, please contact Melissa Schweitzer at IDF, 800-296-4433, ext. 219.

IDF invites the entire community, including patients, providers, manufacturers and distributors to join our efforts in securing equal and adequate reimbursement in all sites of service, by contacting Michelle Vogel, Director of Government Affairs, 800-296-4433, ext. 205.

IDF would like to make sure you are on the mailing list. Please visit www.primaryimmune.org to update your information in the guest book of the website or call the national office at 800-296-4433. Please be sure to include your email address.
Living with primary immune deficiency disease requires state-of-the-art medical care, provided by primary care physicians and immunologists knowledgeable about these diseases and the standard of care for many affected individuals, Intravenous Immunoglobulin Therapy (IGIV). Coping with the emotional and psychosocial impacts of these disorders requires resilience. Resilience is the capacity to bounce back from trauma, adversity, or the significant stress that chronic, life-threatening illness can bring to the lives of those with PIDD, their loved ones and other caregivers. Resilience cannot be infused intravenously, but it can be learned.

Resilience is not to be confused with “feel good” approaches to wellness that deny the reality of genuine human suffering (Lazarus, 1984). Rather, resilience involves facing the realities of adversity as well as the painful emotions that often result. Rather than denying these realities, resilience involves facing them, with the tools needed to deal with them effectively. Following the traumatic events of September 11, 2001, the American Psychological Association (APA) initiated a nation-wide campaign to inform the public about resilience in the lives of ordinary people facing extraordinary events.

Resilience is a process of adapting to adversity. It is not a trait that some people are born with and others are not. For people with PIDD, this process is part of the lifelong journey, involving different adaptations and strategies throughout the life span. Whether you are a middle aged working adult who has to reduce working hours or consider early retirement to cope with fatigue and chronic infections, a college student who has missed one or more semesters due to illness, or a young mother whose marriage is in distress because of her health, learning strategies for developing resilience can help. Understanding the role of close, supportive relationships, both within the family and beyond, is an important ingredient in living well in each of these situations.

Research, according to the APA, suggests that close relationships are key ingredients in developing resilience. Reaching out to loved ones can be an important part of this process. When marriages are troubled, the support of extended family, and professional counseling from providers who understand the ravages of chronic illness, can be essential. And, for the college student, close relationships with peers, student support services, and college and university counseling and health resources can be equally essential. It is vitally important to establish good communication with caregivers, health care providers, and other professionals who are part of your support system. Because so little is known about PIDD, providing information about your condition to professionals who may not otherwise understand what you are experiencing is advisable.

Careful planning is an important part of your “resilience tool-kit” for managing life with PIDD. Taking the presence of PIDD into account in educational, career, and retirement planning, based on prior health experience, can reduce some of the stress that can occur if goals become unreachable. The ability to make plans, carry them out, often in incremental steps, can aid in maintaining confidence and a positive view of oneself. Success in coupled relationships depends on each person having a deep knowledge and understanding of the other (Gottman, 1999). The chronicity and heritability of PIDD therefore requires partners to be intimately aware of PIDD in general, and the health challenges facing the person with PIDD and therefore the couple into the future. It cannot be denied that the stress, uncertainty and losses associated
**A Cuban Feast in Colorado**

On September 18, 2004, Patti Guetz, IDF Volunteer, and her sister Marcel Dorsey hosted a poolside Cuban dinner in Greenfield Village, Colorado to benefit the Immune Deficiency Foundation. Approximately 75 individuals attended the event underwritten by Health One. The guests enjoyed Mojitos and Cuban delicacies and were entertained by a fire dancer later in the evening. A special wine cellar auction concluded the evening.

The guests had the opportunity to learn more about primary immune deficiency diseases as Patti Guetz shared her family’s personal experience with PIDD. Jennifer Scharpf, IDF’s Vice President of Patient Services, provided an overview of the mission and goals of the IDF.

The evening was a wonderful success and raised over $10,000 in support of the Immune Deficiency Foundation. IDF wishes to extend a special thanks to Patti Guetz, Marcel and Jeff Dorsey and Health One for their support of the Immune Deficiency Foundation!

**Stars of Hope and Healing**

The First Annual Stars of Hope and Healing Gala in Minneapolis, Minnesota generated over $130,000. The gala launched the Marvin Shapiro Mid-West Memorial Fund on September 18, 2004. The gala was attended by more than 500 people. There was an amazing silent and live auction, an exquisite dinner and an entertaining show. Some of the local Minneapolis sponsors were The Manhattan Toy Company, Wixon Jewelers, The Cavalier Foundation and several others. A special thanks to the many volunteers that made this special event possible.

This event was a wonderful way for the community to share hope, healing and inspiration with families who live with primary immune deficiency diseases.

**GUND® Bear Fundraiser**

On October 30, 2004, South Carolina Independent Avon Sales Representatives, Sally Blumenburg and Deb Westbury, launched their GUND® Bear fundraiser. They hope to raise more than $40,000 by selling these cute and cuddly GUND® teddy bears. They are also sharing information with their community on primary immune deficiency diseases and the Immune Deficiency Foundation.

**Promises Shared**

Promises Shared in Minneapolis, Minnesota generated over $10,000 in support of PIDD. BioLife Plasma Services participated in the Promises Shared program and raised $3,000 for IDF and the primary immune deficiency disease community. The Promises Shared Program is designed to inspire hope and increase awareness and education of primary immune deficiency diseases. The symbol of hope and healing is a silver star attached to a small chain. If you would like to participate in Promises Shared, please contact Amaris Glenn at 800-296-4433 ext. 317.

**Devin’s Walk-for-Awareness**

IDF Volunteer, Kathy Grizky, recently held a Walk-for-Awareness, in Dorothy, New Jersey. The walk-a-thon included games and face painting for the kids. Great food was enjoyed by all. When asked about the event Kathy said, “Our event was fun, but most of all, we managed to increase awareness of PIDD in our community, which
to me is the most important thing. Because of our event, three families whose children are frequently sick have been tested for primary immune deficiency diseases.”

**Lace Up For PI**
Lace Up for PI was held on September 24, 2004 along the West Haven shoreline in Connecticut. Participants of the 3-mile walk raised $4,000 at Evelyn Maselli and Terri Lowell’s first annual Lace Up for PI event. Lace Up for PI is their newest version of Spin For The Cure. Sponsors included Bayer Healthcare and a local ABC affiliate, News Channel 8. Terri and Evelyn look forward to their wine tasting and auction spring fundraiser in April.

**Quilt Raffle**
The Friendship Quilters of Sun City, Arizona are making a quilt to benefit the IDF's patient community. The warm and colorful bed quilt will be auctioned or raffled off at the Third IDF National Conference in Orlando. IDF would like to thank Dona McCready-Lewis, president of Friendship Quilters, for working with IDF to increase awareness and education of primary immune deficiency diseases. IDF would also like to thank Friendship Quilters for their hard work and interest in helping organizations like the Immune Deficiency Foundation.

If you would like to hold a special event for IDF, please contact Amaris Glenn at 800-296-4433 ext. 317.

NEW IDF PUBLICATION:
A GUIDE FOR NURSES ON IMMUNE GLOBULIN THERAPY

The Immune Deficiency Foundation is pleased to announce its new publication, A Guide for Nurses on Immune Globulin Therapy. According to the Immune Deficiency Foundation’s 2003 national survey, most IGIV infusions are given either at home or a hospital, with nearly 90% of infusions administered by nurses. The IDF’s Nursing Advisory Committee developed this educational booklet to provide essential and current information on immune globulin therapy with the goal of improving the quality of care for patients with primary immune deficiency diseases.

The booklet contains the following informative chapters: clinical uses for IGIV therapy; IGIV preparations; delivery of IGIV; side effects of IGIV; and concomitant medications. A current table listing the characteristics of IGIV products licensed for use in the U.S. is also included.

The booklet will be widely distributed to nursing professionals administering IGIV therapy and is available on the IDF website at www.primaryimmune.org. Nursing professionals may also contact IDF at 800-296-4433 to receive this new publication.
The 2004 Family Retreats provided more than 650 individuals and families the opportunity to relate to others with their same or similar diagnosis, to build relationships and share their experiences. Sixteen immunologists from across the country offered their expertise to help patients and families “Maintain the Balance” in Pennsylvania, Oregon, Texas and Georgia.

During the first retreat ever held in Texas, Carol Ann Demaret, Board of Trustees and mother of David Vetter, gave the keynote address and was an inspiration to attendees. Participants had the opportunity to hear of Demaret’s experiences with her son, David, and his battle with SCID first hand. Immunologists from Texas, Arkansas and Oklahoma including Dr. Mary Paul, Dr. Stephen Miles, Dr. Terry Harville, Dr. James Love and Dr. Robert Sugarman, as well as Dr. Richard Schiff and Dr. Melvin Berger led scientific educational sessions and spent the weekend interacting with the families. One hundred percent of participants stated that they felt the presentations were relevant to their situation and provided valuable information. Participants also said that they learned new and useful information and would recommend the IDF Family Retreat Program to others.

In Georgia, representatives from the Centers for Disease Control and Prevention (CDC) held a panel discussion to introduce future programs involving newborn screening for primary immune deficiency diseases. Immunologists from Florida, Georgia and Alabama joined patients and families to offer informational sessions on topics ranging from understanding antibiotic therapy to managing associated complications of primary immune deficiency disorders. IDF thanks Dr. Robyn Levy, Dr. Suzanne Skoda-Smith, Dr. Harry Schroeder and Dr. Melvin Berger for sharing their time and expertise with the families in Georgia.

Thanks to all that participated and made the 2004 IDF Regional Family Retreats possible. We look forward to seeing all of you at the Third IDF National Conference in Florida, June 23 – 25, 2005.

The 2004 Regional Family Retreats were sponsored by the American Red Cross, Baxter Healthcare Corporation, Bayer Healthcare, FFF Enterprises, Inc., Primaryimmune Services, Inc. and ZLB Behring.

USIDNET: One Year Old!

The United States Immune Deficiency Research Network (USIDNET) marked its first anniversary on October 11, 2004 in Bethesda, Maryland, with an evening meeting and review. Members of the Steering Committee including the Project Officer from NIAID and the Program Officer from NICHD attended the event supported by IDF staff. The meeting attendees included representatives of patient groups who have agreed to serve as Patient Advisors for the Steering Committee.

Suzi Kindregan represented the Ataxia Telangiectasia group, Barbara Meade represented Chronic Granulomatous Disease, Marcia Boyle represented the Immune Deficiency Foundation, Fred and Vicki Modell represented the Jeffrey Modell Foundation, and Barbara Ballard represented the SCIDs Network. Research Grants, the Registry, the Repository, and the Mentoring Program were reviewed. To date, nine research awards have been made. The Registry data collection forms are being updated and implemented. The Repository has been created and informed consent issues addressed. A “Summer School” was held for 30 physician scientists interested in following a career in the primary immune deficiency diseases.

Much progress has been made this year with next year promising to be even more productive with additional sites for scientific presentations and collaborations. Support for research and programs for primary immune deficiency diseases has never been stronger.
Resilience requires facing these emotions and learning strategies for managing them. Having a solid support system can allow for sharing these feelings. Mutually supportive relationships also provide opportunities to give support to others which can be an ingredient in sustaining a positive view of oneself through difficult times.

This is the first in a series of articles on coping with primary immune deficiency diseases by Dr. Nettles for the IDF Advocate. If you have questions or topics you would like to have addressed in this column, you may write to Dr. Nettles c/o Immune Deficiency Foundation, 40 W. Chesapeake Avenue, Suite 308, Towson, MD 21204 or call 800-296-4433.

Dr. Nettles is a psychologist in private practice in Columbia, MD, and a professional life coach. He is also one of the oldest known survivors of X-Linked Agammaglobulinemia (XLA).
Mark your Calendars

The Immune Deficiency Foundation’s 3rd National Conference will be held June 23-25, 2005 at Disney’s Contemporary Resort in Lake Buena Vista, Florida. Registration materials will be mailed in January 2005 and will be available on-line at www.primaryimmune.org.

This year’s conference will celebrate the Immune Deficiency Foundation’s 25th Anniversary. The conference theme “A Legacy of Firsts” reflects on the significant impact the Immune Deficiency Foundation has made in advancing medical research and serving individuals and families affected by primary immune deficiency diseases.

Please call IDF at 800-296-4433 for more information about the National Conference.

We look forward to seeing you in Florida!

A Special Thanks to Our Conference Sponsors

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