

IMMUNE DEFICIENCY FOUNDATION

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 was struggling to care for my son, who was diagnosed with X-Linked Agammaglobulinemia. At that time, there was practically no information about this disease; in fact, I could hardly pronounce it! Fast forward to 2006, my son 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 world class treatment and state-of-the-art facilities for patients with primary immunodeficiency diseases. We launched the *Primary Immune Tribune*, an e-newsletter to provide timely information and our innovative *Diagnostic & Clinical Care Guidelines for Primary Immunodeficiency Diseases* was published. Even the challenge to restore patient access to intravenous immunoglobulin therapy was met with 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 reaffirm 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."

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



The National Patient Organization for Primary Immunodeficiency Diseases



Immune Deficiency Foundation

For twenty-seven years, the mission of the Immune Deficiency Foundation (IDF) has been to improve the diagnosis and treatment of individuals affected by primary immunodeficiency diseases through research, education and advocacy. All of our programs are developed 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 and their families find and acquire the resources they need for daily living. IDF answers inquiries about diagnosis, treatment, and health insurance, as well as requests for information and peer support.

The volume of questions and requests from individuals needing help swelled 125%, or almost 6,000 requests. More than 200 packets of educational resources were sent to patients each month.

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

- Patient

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.

Over 600 personal peer support connections were developed through IDF Volunteer Network.

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

- IDF peer support recipient and now, IDF volunteer

Volunteerism—increasing awareness, raising funds, providing support

IDF could not exist without our nationwide 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, was embraced nationally by organizations, businesses and plasma centers, where donors are thanked for their "gift of life".

IDF awarded scholarships to 43 undergraduate students. The scholarship is open to patients with a primary immunodeficiency disease.

"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."

- IDF volunteer

Patient Education—resources for living with primary immunodeficiency diseases

IDF encourages patients, from 5 year olds to adults, to learn more about living with primary immune disease. Leading immunologists address treatment and management of the disease, while insurance specialists, public policy experts and other qualified professionals focus on life management issues. But, perhaps most important, our meetings provide the opportunity for patients and families to come together and share ideas and encouragement.

Approximately 2,000 patients, family members and others attended IDF meetings in 44 cities across the country in 2006. Family Retreats Weekends in Virginia and Colorado attracted people from 29 states.

“It was great! Meeting others who are living with primary immune deficiency and knowing that neither my husband nor I are alone in this really helps.”

- Patient at a Family Retreat

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 disease. In 2006, *IDF Diagnostic and Clinical Care Guidelines for the Primary Immunodeficiency Diseases*, the first comprehensive guidelines on these diseases, was published and given to over 8,000 healthcare professionals and families. Our *Guide for School Personnel: Primary Immune Deficiency Diseases* was eagerly welcomed by parents and school systems.

The *Primary Immune Tribune*, IDF's new e-newsletter launched in 2006, has quickly become one of the best ways to keep people current with IDF events and news. Our web site continues to be extremely popular, receiving approximately 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.

“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.”

- Rebecca H. Buckley, M.D.
Center Director, Professor of Pediatrics and Immunology at Duke University Medical Center

Consulting Immunologist Program—Valuable Advice from Expert Immunologists

Since 1998, IDF's Consulting Immunologist Program has provided free expert consultations to any physician requesting assistance in primary immunodeficiency diseases. Through this unique program, patient-specific questions and valuable diagnostic, treatment and disease management information can be received from expert clinical immunologists.

Growing in popularity, the number of Consulting Immunologist requests increased more than 40% over 2005, with almost 90 requests last year

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

- Physician

LeBien 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 hospital Grand Rounds and other educational activities, such as medical resident conferences, for their healthcare professionals.

Last year, the LeBien Visiting Professor programs reached approximately 1,000 physicians at hospitals throughout the nation.

“The Visiting Professor visit 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.”

- Physician from a university teaching hospital

Advancing IDF Education—new publications

In partnership with expert immunologists, IDF 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 expand and revise the *IDF Guide for Nurses on Immune Globulin Therapy* to include new replacement therapy options, also available in June.

IDF exhibited at eight national medical association conferences. Medical education packets were distributed to over 3,000 healthcare professionals.

US Immunodeficiency Network—Advancing Scientific Knowledge

IDF administers the US Immunodeficiency Network, an international consortium established to advance scientific research in the primary immune deficiency diseases through peer reviewed research grants, education and mentoring programs, DNA and cell repository, and 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.

In 2006, nine USIDNET research sub-contracts were awarded with a total value of \$2.7 Million. Program total to date represents 27 research sub-contracts awarded totaling \$7.58 million since October 2003.

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

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 this reduction affected them and presented the results. Cited by the Centers for Medicare and Medicaid Services (CMS) as evidence of the hardships, the survey findings helped persuade CMS to issue final rules to continue the temporary “pre-administration-related services” add-on for IGIV in 2007.

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

The 2006 IDF Patient Survey found that IVIG patients on Medicare, when compared to their private pay insurance counterparts, are much more likely to report having IVIG therapy postponed, treatment intervals increased, and their IVIG dosage decreased. As a direct result, they suffered significantly more cases of:

- pneumonia
- bronchitis
- increased use of antibiotics
- infection

The likelihood and number of health problems experienced by PIDD patients is directly correlated with their difficulties in obtaining IVIG.

IDF Capitol Hill Day—Raising awareness in Congress

In April 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 newborn screening.

On IDF Capitol Hill Day, 144 meetings took place and 110 Members of Congress were briefed by IDF volunteers.

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 Hearings 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 this problem has persisted for over two years and little has been done to restore access to IVIG in all sites of care and end the nightmare that has devastated our community.”

- Marcia Boyle
President & IDF Founder

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, a lobbying firm focused exclusively on health care legislation at the Federal Government level.

More than 2,000 letters were sent to Congress from IDF Grassroots Volunteers through IDF Action Alert, our online tool.

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 IDF Action Alert program, our web site’s advocacy tool, has mobilized our community to communicate directly with their members of congress.

2007 CIRCLE OF SUPPORT

Baxter Healthcare Corporation

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Talecris Biotherapeutics

*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.*

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