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.

The Immune Deficiency Foundation, 40 West Chapeau Avenue, Suite 308, Towson, Maryland 21204
Toll-Free 800.321.4433

President's Message

If anyone had told me when we began the Immune Deficiency Foundation in 1980 that IDF would grow into such a vibrant, active organization, I probably would not have believed them. I never thought 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, literally, “There is no disease”). Fast forward to 2006, I was in healthy, married and pursuing my 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 were published. Even the challenge to ensure 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 difference we are making in the lives of those with PID.

“...never was the need to continue our mission been clearer or more urgent...”

Marcia Boyle

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

2006 highlights

More than 2,500 letters were sent to Congress from IDF Grassroots Advocates through our “Take Action Now!” campaign.

IDF Grassroots Advocates sent 313,396 emails, more than 110,000 faxes and 110 Members of Congress were briefed by IDF volunteers.

On IDF Capitol Hill Day—the most action packed day of the year—85 volunteers spoke with 144 members of Congress representing 36 states.

Lobbying—Leadership & Grassroots Volunteer Advocacy Network

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

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

The 2006 Patient Survey found that PID patients on Medicare, who compared to their private pay insurance counterparts, are much more likely to report facing IVIG therapy postponement, treatment interruption, and lower IVIG reimbursement. As a direct result, they suffered significantly more cases of:

- Infections
- Increased use of antibiotics
- Interventions

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

IDF Capitol Hill Day—Raising awareness in Congress

In 2006 more than 800 IDF volunteers went to Capitol Hill to educate their members of Congress about primary immunodeficiency diseases. Hearing the volunteers’ stories proved invaluable in determining the critical need for Congress to support initiatives for improved IVIG reimbursement rates and support for research funding.

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

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

IDF Patient Survey—Giving IDF a voice

When Medicare reduced intravenous immunoglobulin therapy (IVIG) reimbursement rates, IDF surveyed patients to discover how this reduction affected them and provided the results. Currently the Centers for Medicare and Medicaid Services (CMS) is aware of the hardships, as the survey findings helped persuade CMS to issue final rules to continue the temporary "pre-administration related services" add-on code P0270 in 2007.

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**Immune Deficiency Foundation**

For twenty-six years, the mission of the Immune Deficiency Foundation (IDF) has been to improve the lives 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 necessary treatment they need for daily living. IDF answers inquiries about diagnosis, treatment, and health insurance, as well as requests for information and peer support.

“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.”

**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, trained in peer support skills, are prepared to help others in the primary immunodeficiency community.

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

**Volunteerism—increasing awareness, raising funds, providing support**

IDF could not exist without the dedicated efforts of its 1,200 volunteers. Many serve as peer support volunteers; others advocate for public policy and planned educational events.

“The volume of questions and requests from individuals needing help tripled 125%, or almost 6,000 requests.

Over 550 peer support volunteers answered questions from 956 individuals last year.

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**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 diseases. In 2006, IDF Diagnostic and Clinical Care Guidelines for Primary Immunodeficiency Diseases, the first comprehensive guidelines in these diseases, was published and given to over 9,000 healthcare professionals and families. Our Guide for School Personnel, Primary Immune Deficiency Disease was eagerly welcomed by parents and school systems.

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

The volume of questions and requests from individuals needing help tripled 125%, or almost 6,000 requests.

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**New IDF Center of Excellence—Duke University Medical Center**

In 2006, IDF opened the IDF Center of Excellence at Duke University Medical Center with the goal of early diagnosis and improving treatment and care for patients at Duke University Medical Center. The Center offers the services of all 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 goal to offer the best available options for accurate, diagnostic of primary immunodeficiency diseases, to deploy the molecular causes, and to create the optimum and most effective treatment for these patients.”

**Medical Programs**

**Consulting Immunologist Program—Valuable Advice from Expert Immunologists**

Since 1978, IDF Consulting Immunologist Program has provided free expert consultations to any physician requiring assistance in primary immunodeficiency diseases. Through the unique program, patient-specific questions and diagnostic, treatment and health insurance information can be received from expert clinical immunologists.

“It was great! Meeting others who are living with primary immunodeficiency diseases who understand what my husband and I are alone in this really helps.”

**Proven research—consulting immunologist programs reached more than 60% over 2005, with increased requests last year.”**

**LeBlen Visiting Professor Program—Promoting Medical Knowledge and Awareness**

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

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

**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.

**US Immunodeficiency Network—Advancing Scientific Knowledge**

IDF administers the US Immunodeficiency Network, an international consortium established to advance scientific research in the primary immunodeficiency diseases through peer-reviewed research grants, education and medical awareness programs. CNRL and cell regulatory, 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.

**.curriculum. His approach … was clearly presented and easily applied. He answered questions effectively, and challenged the audience appropriately. We truly valued every aspect of this visit.**

**Newly established at eight national and regional conferences. Medical education grants were awarded to over 2,000 healthcare professionals.**

In 2006, six USIDNET research sub-contracts were awarded with total awards of $2.5 million. Program took to state representatives. IDF research sub-grant, awarded through the NIH, exceeded $1.8 million since November 2002.

**The Immune Deficiency Foundation thanks its Board of Trustees, Medical Advisory Committee, Nurse Advisory Committee, volunteers, sponsors, staff and our many generous supporters.**
For twenty-seven years, the mission of the Immune Deficiency Foundation (IDF) has been to improve the health of patients and their families affected by primary immunodeficiency diseases through research, education, and advocacy. All of our programs are designed to support this mission and meet our goals.

**Patient and Family Programs**

**Patient Advocacy—IDF’s heart and focus**

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

“...I first turned to the Immune Deficiency Foundation 14 years ago when I was newly diagnosed...”

Today, when I called about being treated for a new disease, IDF was there to help, support and advise.”

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

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

“My IDF peer support volunteer was a young mother with CVID who was my inspiration. She had so much energy and was so...”

**Volunteerism—increasing awareness, raising funds, providing support**

IDF could not exist without the dedicated service of all its IDF volunteers. Many serve as peer support volunteers; others advocate for public policy, and plan meetings and other events. Special programs, such as the IDF Volunteer Network, are 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...”

**Patient Education—resources for living with primary immunodeficiency diseases**

IDF provides a variety of educational materials for adults, to learn more about living with primary immunodeficiency disease. Leading immunologists address treatment and management of the immune disorder, while insurance specialists, public and private experts and other qualified professionals focus on the management issues. But, perhaps most important, our meetings provide the support and hope for patients and families to come together and share ideas and encouragement.

“It was great! Meeting others who are living with primary immunodeficiency disease and knowing that neither my husband nor I...”

**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, a comprehensive source of guidelines on these diseases, were published and given to over 9,000 healthcare professionals and families. Our Guide for School Personnel: Primary Immunodeficiency Disease was eagerly welcomed by parents and school systems.

**Patient at a Family Retreat**

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**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 in Duke University Medical Center. The Center offers the services of all the world’s leading experts and state of the art facilities focusing on research and clinical care of primary immunodeficiency diseases.

“They through the IDF Center of Excellence, we will continue to pursue our goal to offer the best possible care for patients with a primary immunodeficiency disease.”

**Consulting Immunologist Program—Valuable Advice from Expert Immunologists**

Since 1990, the Consulting Immunologist Program has provided free expert consultations to any physician requesting assistance in primary immunodeficiency diseases. Through the unique program, patient-specific questions and valuable diagnostic, treatment and disease management information can be received from expert clinical immunologists.

“...we are all one really! I am so honored that you have included me in your circle of help.”

**Medical education packets**

IDF exhibited at eight national medical association conferences. Medical education packets were distributed to over 2,500 healthcare professionals.

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

Volunteerism—increasing awareness, raising funds, providing support

Volunteerism is open to patients with a primary immunodeficiency disease. In 2006, IDF’s volunteer program was expanded to include a Volunteer weekend at the late Gary L. Shuler Volunteer Family Retreats. Approximately 2,000 family members, patients and friends attended over the three year period.

“Im IDF peer support volunteer was a young mother with CID with no experience. 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.”

The joy of patient volunteers and IDF family and friends in helping others

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Patient Education—resources for living with primary immunodeficiency diseases

IDF reports are available online at www.idf.org, at no charge to the public, to learn more about living with primary immunodeficiency disease. Leading immunologists address treatment and management of the immune disorder, while insurance specialists, public and private experts and other qualified professionals focus on the management issues. But, perhaps most important, our meetings provide the opportunity for patients and families to come together and share ideas and encouragement.

“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.”

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The Primary Immunodeficiency Tribune, IDF’s new e-newsletter launched in 2006, has proved to be one of the best ways to keep people current with IDF events and news. Our web site continues to be extremely popular, receiving on average approximately one million hits each month. The IDF Advocate, our traditional newsletter is published three times a year and has a circulation of 25,000.

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Advancing IDF Education—new publications

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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, Cohn 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.

Consulting Immunologist Program—Valuable advice from expert immunologists

Since 1995, IDF’s Consulting Immunologist Program has provided free expert consultations to any physician requesting assistance in primary immunodeficiency diseases. Through the unique program, patient-specific questions and valuable diagnostic, treatment and disease management information can be received from expert clinical immunologists.

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

LeBlon Visiting Professor Program—Promoting Medical Knowledge and Awareness

The Visiting Professor Program contributes to and presents 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.

“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.”

In 2006, IDF exhibited at eight national medical association conventions. Medical education packets were made available to over 3,000 healthcare professionals.

In 2006, six USIDNET research sub-contracts were awarded totaling approximately $1.0 million. Four research sub-contracts were awarded totaling $3.2 million, and awarded totaling $1.6 million between Oct 1, 2003 and Oct 1, 2004.
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.

2006 highlights

"I'm grateful I found your foundation. I already don't have blood infections, but I couldn't have said that 3 years ago. I didn't know if I was going to live, but now I lead a normal life thanks to Immunodeficiency Foundation in 1980 that IDF would grow into such a vibrant, active organization, I probably wouldn't have believed them... I was fighting a battle for care for my son, who was diagnosed with Agammaglobulinemia. At that time, there was practically no information about this disease; in fact, it made it impossible to find treatment. In 2006, we was in healthy, warm and pursuing the career I would have had never been a way of life for doctors and patients with primary immunodeficiency diseases. We launched the Primary Immune Tribune, an e-newsletter and public awareness program to raise awareness of primary immunodeficiency diseases. 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: "The Immune Deficiency Foundation is surely the most important organization I've found for their work on primary immunodeficiency diseases and meet future challenges. 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

Marcia Boyle
President & Founder
Immunodeficiency Foundation
The 2006 IDF Patient Survey found that HDI patients on Medicare, who compared to other private pay insurance counterparts, are much more likely to report being AV therapy postponed, treatment interruptions, and lack of IVIG Access. As a direct result, they suffered significantly more cases of:

- Infections
- Increased use of antibiotics
- Hospitalizations

The Risk Survey identified and numbered health problems experienced by HDI patients in direct correlation with their difficulties in attaining IVIG.

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

IDF Capitol Hill Day—Raising awareness in Congress

In 2006, more than 200 volunteers went to Capitol Hill to educate their members of Congress about primary immunodeficiency diseases. Hearing the volunteers’ stories proved invaluable in detailing the critical need for Congress to support initiatives for improved IVIG reimbursement rates and support for research funding.

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

Marcia Boyle, President of IDF, was a frequent voice on behalf of primary immunodeficiency patients who need IVIG. She testified at hearings at the House Ways and Means Subcommittee on Health, Senate Committee on Finance, and Public Health. She also helped 91 Members of Congress learn about the importance of primary immunodeficiency diseases, hearing the volunteers’ stories.

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.

The likelihood and number of health problems experienced by PIDD patients include:

- Infection
- Increased use of antibiotics
- Bronchitis
- Pneumonia

The 2006 IDF Patient Survey found that PIDD patients on Medicare, who compared to other private pay insurance counterparts, are much more likely to report being AV therapy postponed, treatment interruptions, and lack of IVIG Access. As a direct result, they suffered significantly more cases of infections.

IDF lobbyists have met with over 300 state legislators and 118 Members of Congress who are in direct contact with primary immunodeficiency patients by IDF volunteers.

IDF lobbyist—Leadership & Grassroots Volunteer Advocacy Network

In 2006, IDF played a leadership role in mobilizing providers, advocates, industry and patients living with primary immunodeficiency diseases 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.

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2007 CIRCLE OF SUPPORT

Baxter Healthcare Corporation

CSL Behring

Grifols

Octapharma

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.

Thank you to everyone involved with IDF. I am grateful for your continued support and encouragement as we work to meet current challenges and meet future challenges. The National Patient Organization for Primary Immunodeficiency Diseases

Marcia Boyle

President & Founder

Immune Deficiency Foundation

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Toll-Free 800.296.4433

www.primaryimmune.org

The Immune Deficiency Foundation is a publicly supported, non-profit organization as described under section 501(c)(3) of the Internal Revenue Code of 1986, as amended.

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 find my voice. I was diagnosed with X-linked Agammaglobulinemia. At that time, there was practically no information about this disease. In fact, I considered myself fortunate to find out about it in 1980. My life was in healthy, energetic and pursuing my career and IDF could not have been

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 Immunodeficiency Blood Safety Program to provide timely information and our innovative Diagnostic & Clinical Care Guidelines for Primary Immune Deficiency Diseases were published. Even the challenge to ensure 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 with you a story and reaffirm your commitment to IDF, I want to share with you a quote from one of our patients that resonated with me. ‘I am grateful I found your foundation. I already don’t feel 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.

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