“Hanging Up Jeans” Saves Lives!

Each year, the Immune Deficiency Foundation (IDF) has jeans for healthy immune system awareness. People can "hang up" the jeans to ask their physician to examine their immune system.

Survey Research

With the unique ability to reach national samples of patients and healthcare professionals in our vast database, the IDF survey research center was formally established in 2007 to provide timely and accurate analysis on issues of importance to the primary immunodeficiency community.

Perhaps our most significant study, Population Prevalence of Primary Immunodeficiency Diseases, was published on the occasion of the 20th anniversary of the IDF. The results of this landmark study were reported in a peer-reviewed article by Dr. Rebecca Buckley and Dr. John Boyle in the September 2007 Journal of Clinical Immunology.

IDF distributed reports to Congress from 1994 to 2001 to Access IVIG, a visibility and access issue specific to primary immunodeficiency. On Capitol Hill, IDF spearheaded the introduction of H.R. 2914, the Medicare IVIG Access Act, in the House of Representatives.


Public Policy Advocacy

Landmark Legislation Introduced

Through our Web-based Action Alert Program, our grassroots advocacy volunteers sent over 8,000 letters to Congress urging legislators to help put an end to the IVIG access issue.

IDF volunteers visit plasma centers nationwide, share their stories and thank the donors for their incredible gift of life-saving plasma.

The groundbreaking survey was repeated twice in 2007 to provide timely and accurate analysis on issues of importance to the primary immunodeficiency community.

The Primary Immunodeficiency Diseases in America Survey, 2007 followed up on the 1994 and 2002 IDF patient surveys. These surveys have been held every 5 years and continue to be invaluable resources that have evaluated the characteristics and state of primary immunodeficiency diseases in the U.S.

The IDF Prevalence Study suggests that:

• Primary care health providers should expect to identify PID patients correctly and should be on alert to identify PID as a possible underlying cause for frequent, repeated or unusual infections in their patients;

• Only a minority of PID patients with antibody deficiencies are being treated with immunoglobulin replacement, pointing to a serious problem of under-treatment of PID patients in the general population;

• The prevalence rate is sufficiently high enough that a strong case can be made for more systematic screening for these diseases.

International Outreach

long recognized as a leader in the international arena, IDF plays a critical role in the International Primary Immunodeficiency Organizations (IPISO).

As part of the Executive Committee of IPISO, Marcia Boyle chairs IPISO’s Product Safety, Supply and Affordability Committee (PSAC).

In 2006, Marcia Boyle shared the stage with a panel of experts at the 15th International Congress on Primary Immunodeficiency Diseases, where she was invited to participate in a panel discussion and to share her expertise with an international audience.

While the topic of the session was primary immunodeficiencies, Marcia Boyle was poised to lead the way.

IDF granted a license to IPISO to use material from the new 2007 IPISO Patient Handbook. Going forward, the handbook will be available in multiple languages and will be distributed to key health professionals in the countries where the IPISO membership is located. Copies may be requested through info@ipopi.org.

As part of IPISO’s international outreach efforts, Marcia was invited to lead a panel discussion at the 15th International Congress on Primary Immunodeficiency Diseases held in Auckland, New Zealand in July.

The Immune Deficiency Foundation was invited by the Board of Directors of the Pediatric Advisory Committee, Nurse Advisory Committee, and Patient Advocates to share information, staff and the many resources and services for the primary immunodeficiency community.

We move into 2008 with great momentum created by these accomplishments and continue our dedication to ensuring that all patients with primary immunodeficiency can receive the treatment they need.

Immune Deficiency Foundation 2007 Highlights

A Message From Our President

At the lead of the organization that works to improve the lives of individuals with primary immunodeficiency diseases, one of the most frequent questions posed to me is how many people in the United States have primary immunodeficiency disease? Now, this is a perfectly logical question to be asked, but you would think I should be able to respond with confidence. But, frankly, the answer isn’t that clear. And, in the world of science, it’s even more confusing for this debate or any time during life.

In addition, the survey will collect information on primary immunodeficiency diseases. And able IDF has surveyed patients in our database concerning their condition and treatment experiences; there has been comprehensive study of primary immunodeficiency diseases in the general U.S. population. For years, we had no reliable estimates.

This year, the Health Care Financing Administration probability survey of 150,000 households to determine the frequency and to measure the prevalence of primary immunodeficiency diseases in the U.S. Surprisingly, the numbers were much higher than we had anticipated. The findings revealed a population prevalence of 1 in 2,600 persons. When applied this number to the total U.S. population, it suggested that there are approximately 250,000 people with diagnosed primary immunodeficiency diseases in the country. These findings were published in a peer reviewed journal in September 2007.

Armed with this knowledge, we realized had to be prepared to address the additional needs and issues of such a large population of patients. We need to implement plans and programs to better meet these growing challenges and capitalize on expanded resources.

We are proud of IDF’s many accomplishments last year. It was a year of health aspirations and successes—all of which serves as a strong foundation for the future development of our organization to build on.

Marcia Boyle

President & Founder

Immune Deficiency Foundation

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Immune Deficiency Foundation

Reaching for a Better Future...
IDF Board of Trustees

IDF is a patient-based organization that works toward enhancing and improving the quality of life of persons living with primary immunodeficiency, and the existing mission statement did not reflect that uniqueness of the community. Clearly, many IDF activities help educate the basic well-being of all those who take advantage of these resources. Just because someone is enrolled in the IDF does not mean that they understand the concepts behind the words, "primary immunodeficiency diseases". We believe that they see the association’s mission as a way to fulfill their duties.

The Immune Deficiency Foundation is a national patient organization dedicated to improving the diagnosis, treatment, and quality of life of persons with primary immunodeficiency diseases through advocacy, education, and research.

Patient Advocacy

Since 1980 when IDF was founded, many things have changed. However, one thing remains constant—first and foremost, our main concern is always the patients. All programming and resources are created with our patients and families in mind, with the goal of improving their lives. Primary immunodeficiency diseases have a high impact, affecting many aspects of a person’s life.

In 2007, IDF fielded 4,500 inquiries from people looking to answer a variety of immune and immune disorders. Those ranged from questions about primary immunodeficiency—specific type, treatment, diagnosis—to finding a resource for assistance with the accompanying immune, such as insurance, school, and access to financial assistance. A majority wanted more information and requested IDF’s educational materials. 

In 2007, over 3 million people searched for answers to a variety of immune and immune disorders.

New Educational Resources

The 6th edition of IDF’s Patient & Family Handbook for Primary Immunodeficiency Diseases was inspired by the many new and exciting advances in diagnosis and treatment. The new edition was released in full color in 2007, and of the existing chapters, were reorganized to include information on new diagnostic tools, more precise clinical information and new therapies.

In response to new advances and treatments, the FDA Advisory Committee updated and expanded the IDF Guide for Nurses on Immune Globulin Therapy. This guide provides direction for nurses to administer immune globulin replacement therapy safely and most effective way.

The information at hand is “just in time” for patients to be inquisitive if they have no objection to being informed or curious. In 2007, more than 100 attendees were interested in the new edition and available to talk to other patients, parents or caregivers.

IDF released its new Web site, which contains information about our services, materials and programs, as well as basic information on symptoms of primary immunodeficiency diseases.

Staying in Touch

With over 100,000 medical professionals and patients, IDF is a growing organization that works tirelessly to educate, support and connect with people throughout the United States, and offers services to patients, families, healthcare professionals, and the general public.

IDF’s Web site (www.primaryimmune.org) may be accessed 24/7 for information, resources, and programs. 

IDF’s newsletter, the IDF Advocate, is a monthly publication providing information on the latest medical advances from world-renowned immunologists. 

Medical Education

Medical Advisory Committee

The IDF Medical Advisory Committee is a prominent group of internationally recognized immunologists who provide strategic guidance, medical liaison, and advocacy and educational initiatives. In 2007, several members of the Medical Advisory Committee received special recognition for their work.

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New Educational Resources

In 2007, IDF fielded 6,000 inquiries from people looking for answers to a variety of issues and concerns. Issues ranged from questions about primary immunodeficiency -- specific type, treatment, diagnosis -- to finding a physician, for requests to assistance with the accompanying issues, such as insurance, school, work access, employment discrimination or financial assistance. A majority wanted more information and requested IDF educational/functional materials and 20,000 resources were sent out in 2007.

In 2007, 3,500 patients, family members, healthcare professionals and general public attended IDF educational presentations in 67 cities across the country.

Staying in Touch

With over 10,000 medical and scientific attendees from 60 countries, attendees have the opportunity to network, interact and gain access to people throughout the world. The 2007 IDF Conference was well attended by family members, healthcare professionals and general public and included educational sessions at the conference.

US Immunodeficiency Network

The US Immunodeficiency Network, an international consortium established to advance scientific research in the primary immunodeficiency diseases and to improve care and access to treatment for affected individuals, has grown to 140 centers across the country.

The Immune Deficiency Foundation

The Immune Deficiency Foundation is a non-profit charitable organization dedicated to providing education, support, and research for primary immunodeficiency diseases. IDF funds an irreplaceable network of world-class healthcare facilities dedicated to treating those affected and their families across the United States. IDF is supported by contribution from dedicated donors, physicians and allied health care professionals, corporations, foundations, and the general public.
of particular importance were those who told a more personal touch—telling a little-known, but yet heartwarming, story about someone who had experienced a similar situation. This is where our dedicated Patient Support Volunteers stepped in, providing a much-needed link between patients and family members. Forty-five new peer support volunteers joined our dedicated roster of 70 volunteers in 2007. These trained volunteers are available to talk to other patients, patients’ caregivers.

Patient Education

Since 1980 when IDF was founded, much has changed. However, one thing remains constant—first and foremost, our main concern is always the patients. All programming and research are created with our patients and families in mind, and for the sole purpose of improving their care.

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New Educational Resources

The 6th edition of our Patient & Family Handbook for Primary Immunodeficiency Diseases was published in 2007. This handbook is designed to be a resource for families and or patients and is available online and in print. These updated resources were used in 2007 by patients, family members, healthcare professionals and general public attended the IDF educational presentations in 67 cities across the country.

In 2007, IDF fielded 8,000 inquiries from people looking for answers to a variety of issues and concerns.

With over 400 scientific and medical sessions to choose from, conference attendees learned about medical advancements from world-renowned immunologists. Life management presentations, shared-workshop skills and other disease-related educational panels were created so that children, brothers and (eventually) sisters, and even grandparents can come together to learn about this unique disease community. The educational program, healthcare professionals learned how to improve the recognition, diagnosis, and management of primary immunodeficiencies. And there was plenty of music, dinner, dancing and groundbreaking and enjoyable way to pass through the last few days of the conference. These topics highlighted the importance of patients and family members shared and experienced.

Medical Education

Medical Advise for IDF IDF’s Medical Advisory Committee is a prominent group of immunologists and other experts in the field. Our annual symposium and educational initiatives have been politically and educationally oriented. In 2007, several members of the Medical Advisory Committee received special recognition for their work.

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IDF Consulting Immunologist Program Annual symposium and educational initiatives have been held for the benefit of healthcare professionals at training institutions.

IDF Center of Excellence—Duke University Medical Center The Center for Excellence for Primary Immunodeficiency Diseases at Duke University Medical Center is the world’s largest resource for research and clinical care of primary immunodeficiency diseases, with the goal of improving each patient’s diagnosis and treatment and care for patients.

US Immunodeficiency Network

In the US Immunodeficiency Network, an international consortium established to advance scientific research in the primary immunodeficiency diseases through peer-reviewed research grants. The nurses, doctors, nurses, and other health professionals involved in the treatment and care of patients with primary immunodeficiency diseases. The network is composed of the National Institutes of Health, the Department of Health and Human Services, and the National Institutes of Health, and the Department of Defense, which are components of the National Institutes of Health, an agency of the Department of Health and Human Services.

IDF Board of Trustees

IDF is a not-for-profit organization that works towards enhancing and improving the quality of life of persons living with primary immunodeficiency diseases. The Board, the existing liaison statement did reflect the expertise and community. Clearly, many IDF activities help educate the public, and why all those who take advantage of these resources. Just imagine the number of lives that could be saved if you understand the scope of belonging and positive experiences they experienced.

After a compelling and heart-felt discussion by the board members, it was agreed to make a slight, but significant change to wording of the IDF mission statement. Our board believes that this new statement acknowledges and underscores IDF’s primary goal of putting the patient and their family, first.

The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education, and research.

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Through our Web-based Action Alert Program, our grassroots advocacy volunteers sent over 4,000 letters to Congress urging legislators to help with IVIG access and reimbursement issues.

Public Policy Advocacy

Landmark Legislation Introduced

On Capitol Hill, IDF spearheaded the introduction of Landmark Legislation — H.R. 2914, the Medicare IVIG Access Act, in the House of Representatives — from both political parties — have signed on to cosponsor the bill. As representatives of the primary immunodeficiency community, IVIG access and reimbursement problems now have greater visibility and understanding in both the House and Senate.

We move into 2008 with great momentum created by these accomplishments and continue our dedication to ensuring that all patients with primary immunodeficiency can receive the treatment they need.

Survey Research

The IDF Prevalence Study

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We are proud of IDF’s many accomplishments last year. It was a year of growth in terms of membership and programs to better meet these growing challenges and opportunities.

We remain committed to our mission and will continue to work with you to achieve our goals. We look forward to continuing our partnership with you in the future.

Marcia Boyle
President & Founder

Immune Deficiency Foundation