A Message from our President

Back in 1980, the Immune Deficiency Foundation held its first meeting in a small room at Johns Hopkins Hospital. I think there were about ten people present. I was thrilled! It felt wonderful to talk with others, sharing ideas and experiences, while soaking up any new information we could find. I can still recall the sense of accomplishment I felt organizing it and realizing that it was just the beginning of many more IDF gatherings to come.

Fast forward to 2008: last year, IDF hosted more than 100 educational presentations, in 85 cities, that were attended by approximately 6,000 people. I knew it was a busy year, but even I was taken aback when we added up the numbers. It made me stop and think of how IDF is truly a nationwide community comprised of people throughout the country working on a variety of fronts including educational programs, advocacy efforts, medical services, support systems, and all the pieces needed to help improve the lives of people living with primary immunodeficiency diseases.

People often ask, what is IDF? Perhaps the question should be “Who is IDF?”

Through the commitment and effort of board leadership, volunteers, physicians, healthcare professionals, industry sponsors, donors and staff, we have once again lived our mission in 2008. Everyone is very passionate about providing the highest quality of resources for the primary immunodeficiency community. We have dedicated ourselves to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

I am excited to share with you a few of the highlights during the past year along with some of The Many Faces of IDF.

With your support and encouragement, IDF will continue to reach out in service to our community. It is our honor and privilege.

Marcia Boyle

President & Founder
Immune Deficiency Foundation
We know that finding answers to questions about living with primary immunodeficiency diseases is not easy. This is why IDF makes patients and their families our number 1 priority, and dedicates much of what we do to finding those answers.

IDF fielded more than 7,000 patient inquiries in 2008. People looking for patient education and resources, assistance with health insurance issues and Medicare reimbursement, along with help locating a physician topped the list of reasons individuals contacted IDF. Others needed help with school issues, employment discrimination and other life management concerns.

Perhaps one of the most important services IDF offers is Peer Support. Feeling isolated can be a common reaction for people with a primary immunodeficiency, especially when first diagnosed. When no one else seems to understand, IDF has a committed group of Peer Support Volunteers who are ready to step in and “be there” for the patient, parent or caregiver. They are there to offer understanding, encouragement and often an empathetic laugh to those who also share the common bond of living with these little known diseases.

In 2008, more than 500 personal connections were made between trained Peer Support Volunteers and other patients and family members. This year, thirty-six new Peer Support Volunteers joined our dedicated roster! We now have over 200 experienced Peer Support Volunteers.

Our network of volunteers is central to IDF’s mission. Their commitment and hard work helps the Foundation with programs throughout the country.

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In May, members of our volunteer community gathered in Chicago, Illinois, for the IDF Volunteer Leadership Conference. These dedicated individuals ran the workshops on grassroots advocacy, education, fundraising and promoting awareness. In addition to the enthusiastic peer support, fervent networking and informative seminars, volunteers were treated to entertainment by reigning Miss Wisconsin ANTSO, Samantha Jankins, an IDF volunteer herself. Saturday evening brought a night on the town that finished up at the famous comedy club, Second City for some wonderful laughs!

Four volunteers Jan Christensen, Bonnie Doak and Gail and Syd Nelson were recognized with the “IDF Dedicated Volunteer” awards for serving IDF as volunteers in many capacities.

Grassroots Public Advocacy

In April, more than 50 volunteers from across the country descended on Washington, D.C. for IDF Capitol Hill Day.

In just one day, IDF advocates met with members of 93 legislative offices! The personal stories and experiences they shared with our nation’s lawmakers were invaluable in advancing the causes of the primary immunodeficiency community.

The tireless, determined work of IDF volunteers that day paved the way for the introduction of Senate Bill 2990, the Medicare IVIG Access Act that was introduced on May 7, 2008 by Senators John Kerry (D-MA), Lamar Alexander (R-TN), and Debbie Stabenow (D-MI). This was a companion bill to the House Bill, H.R. 2914, the Medicare IVIG Access Act.

In June, IDF surpassed the milestone of 10,000 letters sent through our Website based Action Alert. Action Alert letters are hand delivered to key congressional offices and are a very effective tool for raising awareness and garnering support to fix the current reimbursement issue.

IDF surpassed the milestone of 10,000 letters sent through Action Alert.
Expanding Our Communications

Although all of IDF’s 2008 achievements are important, one of the more noteworthy was the revamping of our Website. In addition to the new look, www.primaryimmune.org – which now averages more than 1.5 million hits a month - offers each visitor a wealth of information on primary immunodeficiency diseases. This includes downloads of all the IDF publications, and sections where patients & families, or healthcare professionals can find information that is relevant to them. Patients and families now have improved access to educational materials, resources, earlier notification of upcoming events, health advisories and timely information due to the addition of a self-maintained calendar feature.

www.primaryimmune.org – averages more than 1.5 million hits a month

One of the most popular features, the enhanced IDF discussion forum, continues to be the online meeting place for more than 1,500 members to share ideas and provide support. In addition, IDF is in the process of expanding our web presence even further with the creation of an IDF social network, where we will leverage the power of social media to further our mission in areas such as patient education, disease awareness and public policy advocacy.

Our electronic newsletter, Primary Immune Tribune, which currently has 9,300 subscribers, reaches out monthly to keep readers up-to-date and alert them to any late-breaking developments that may affect them in the primary immunodeficiency community. The IDF ADVOCATE, our traditional newsletter, has a circulation of 20,000 and is published 3 times a year.

Expanding Our Communications

In 1990, Sara LeBien’s idea for a children’s book finally came to fruition in Our Immune System, a story for children with primary immunodeficiency diseases. This simple tale of how the immune system works, as well as information about treatments for children with primary immunodeficiency diseases, continues to be the most requested IDF publication. In fact, worldwide demand has resulted in translation in twelve languages.

In 2008, Our Immune System was updated - reflecting the changes in technology, treatment and even in the IDF community itself. The second edition of this publication features not only informational updates, but also colorful illustrations, and is still available free of charge by simply contacting IDF or downloading it from our Website.

Last spring, IDF proudly offered the new issue of Clinical Focus on Primary Immune Deficiencies, a professional education monograph. This issue focused on Subcutaneous IgG Therapy in primary immunodeficiency diseases. Authored by Dr. Melvin Berger, and edited by Dr. Kathleen Sullivan and Dr. R. Michael Blaese, the Clinical Focus is designed specifically for healthcare professionals.

New Publications
Professional Healthcare Education

Nurses can now earn free continuing education credits (CE) thanks to the 2008 introduction of a free Internet course based on the publication, *IDF Guide for Nurses on Immune Globulin Therapy for Primary Immunodeficiency Diseases.*

The CE course, developed by the **IDF Nurse Advisory Committee**, is targeted to certified registered nurse infusionists, registered nurses and licensed practical nurses. Participants receive 1.0 contact hours for their participation in this CE course on Immune Globulin Therapy for Primary Immunodeficiency Diseases found at www.primaryimmune.org.

IDF presented the results from our recent survey of pediatricians at the dinner symposium, “Identification, Diagnosis, Treatment and Management of Primary Immunodeficiency Diseases,” at the **American Academy of Pediatrics National Conference and Exhibition** in October. Faculty presenters included Vivian Hernandez-Trujillo, MD, Jordan Orange, MD, PhD and John Boyle, PhD. This was a perfect opportunity to reach out to pediatricians, often the first healthcare professionals to encounter our littlest patients.

This academic year, expert clinical immunologists through the **LeBien Visiting Professor Program** presented to over 1000 residents, fellows, community physicians and other healthcare professionals at teaching hospitals across the U.S. The United States Immunodeficiency Network Consortium (USIDNet) joined partnership with IDF to co-sponsor this program.

**LeBien Visiting Professor Program 2008**
- University of Illinois at Peoria
- Loyola University – Chicago
- Upstate Medical University
- University of Texas Medical Branch
- Baylor College of Medicine
- Naval Medical Center – San Diego
- University of California, Davis
- Cleveland Clinic Foundation
- University of Hawaii

One-on-one medical education is conducted through the **IDF Consulting Immunologist Program.** This program offers free expert consultations to any physician who requests for one regarding a specific patient with a primary immunodeficiency disease.

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

The IDF Center of Excellence for Primary Immunodeficiency Diseases continued to offer the services of some of the world’s leading experts and state-of-the-art facilities. This program focuses on research and clinical care of primary immunodeficiency diseases with the goal of increasing early diagnosis and improving treatment and care for patients.

**2008 IDF Exhibits at Medical Conferences**
- American Academy of Allergy Asthma and Immunology
- National Association of Pediatric Nurse Practitioners
- Infusion Nurses Society
- American College of Physicians
- American Academy of Pediatricians

**US Immunodeficiency Network**

IDF administers the US Immunodeficiency Network (USIDNet), an international consortium established to advance scientific research in the primary immunodeficiency 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.
The Blue Jeans for Healthy Genes (BJHG) program creates awareness about primary immunodeficiency diseases, encourages a relationship between patients, plasma donors and plasma center employees while raising funds for IDF. In 2008, 183 plasma centers throughout the country participated in this win-win project where everyone plays an important part.

Patients and family members visit plasma centers nationwide, share their stories and thank the donors for their incredible gift of life-saving plasma. Donors and plasma center employees see the importance of the life-saving medications that are produced from plasma and the difference they make in the lives of persons diagnosed with primary immunodeficiency diseases. Patients and family members gain a better understanding of plasma donation and see firsthand the regulations that are in place to produce the safest, highest quality plasma for their life-saving medications.

Through Blue Jeans for Healthy Genes, plasma donors, patients, and employees see the significant roles they play in this continuous “circle of life.” Their combined efforts also help to raise funds for patient education and support programs.

**Participating BJHG Plasma Centers 2008**

BioLife Plasma Services • Biomat USA • ZLB Plasma

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**Knowledge is Power**

IDF knows that members of the primary immunodeficiency community have varied needs and a cookie-cutter approach to programming would certainly not work. In 2008, IDF hosted more than 100 educational presentations, in 85 cities, that were attended by approximately 6,000 patients, family members, healthcare professionals and the public at large. These programs came in a variety of forms. There were volunteer-led patient education meetings, presentations held at plasma centers, Visiting Professor Programs, Family Days, Operation Outreach meetings, exhibits at medical society meetings as well as health fairs and assorted workshops and sessions held throughout the U.S.

Of special interest were the two Family Retreats—incredible weekends of discovery, learning and fun where members of our community came together at the fabulous Gold Canyon Golf Resort (in Gold Canyon, Arizona) and at the Hueston Woods Resort and Conference Center (in the bucolic setting of College Corner, Ohio). These weekends offered something for everyone, including fun, age-appropriate activities, presentations from leading immunologists and life management experts, and time with others who share common therapies and experiences, and offer inspiration.

In 2008, IDF embarked on a project driven by requests from families touched by Severe Combined Immune Deficiency (SCID). The **IDF SCID Initiative** was created to support SCID-specific programs including education, awareness, diagnosis, newborn screening, and the search for a cure. IDF developed an oversight committee for the Initiative fund, and initial contributions helped support the 2008 SCID Conference, held in July at the Wintergreen Resort in Virginia.
IDF’s success as the key resource of authoritative information for patients and their families, as well as the medical professionals who treat them, is largely due to the critical nature of the data IDF has collected from our national surveys.

Thanks to the dedicated patients and families in our community, the IDF database contains the single largest number of contacts in the primary immunodeficiency community. Our surveys produce remarkable results with patient response rates routinely topping 60%. Most IDF surveys are based on more than 1,000 respondents, making the data IDF collects reliable and valid, particularly for a rare disease population. Our data is highly sought after and IDF is often asked to present survey results and data at medical, government and industry meetings all over the world.

In 2008, IDF was asked to contribute an article to the Pharmaceutical Policy & Law Journal. This article, Impact of intravenous immunoglobulin treatment among patients with Primary Immunodeficiency diseases (Pharmaceutical Policy & Law 10 (2008) 133-146, IOS Press) was authored by Marcia Boyle, IDF President & Founder and Chris Scalchunes, IDF Director of Survey Research. This article examined the costs of not diagnosing and treating patients with primary immunodeficiencies.

Data from the IDF 2007 National Patient Survey became available in 2008 and had some interesting results. The average time to diagnosis from symptom onset for patients with primary immunodeficiency disease increased from 9.2 years (IDF 2002 National Patient Survey) to 12.4 years.

Although it might appear as though it is taking longer for patients to become diagnosed this may not necessarily be the case. It is possible that recognition of these diseases has actually improved and adults with “mystery” illnesses have finally received a definitive diagnosis. The 2007 National Patient Survey had a higher proportion of older patients reporting Common Variable Immunodeficiency Disease (CVID) as their diagnosis than in earlier surveys. These findings would be consistent with longer times to diagnosis as those with CVID are more likely to report longer times from symptom onset to diagnosis than those who report other specific primary immunodeficiency disease diagnoses.

Unfortunately, this patient data indicates that the time to diagnosis for patients with primary immunodeficiencies is not improving. It is imperative for patients to receive timely and accurate diagnosis to give them the best possible opportunity to live healthy, productive lives. IDF will continue to dedicate our efforts to promote early and correct diagnosis.

IDF Internationally

IDF plays a leadership role in the International Patient Organisation for Primary Immunodeficiencies (IPOPI). Marcia Boyle serves on the executive committee and chairs IPOPI’s Plasma Product Safety, Supply and Affordability Committee. At their biennial meeting in October in the Netherlands, Marcia presented on the Importance of Collection and Dissemination of National and Global statistics on Primary Immunodeficiency Diseases.

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

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