It may be a cliché, but when it comes to measuring the success of the Immune Deficiency Foundation, the numbers do indeed tell the story.

Our mission statement, affirming our dedicated objective to improve diagnosis, treatment and quality of life for persons with primary immunodeficiency diseases, describes the basic tenets of this organization. However, until one looks at the data behind our ongoing purpose, one can’t fully grasp the impact IDF has had while working on behalf of our community.

In 2009, nearly 5,000 people attended more than 80 Patient Program meetings, including the almost 1,400 strong that were on hand for the IDF National Conference. Among IDF’s patient programs were Education and Support Meetings, Health Fairs, Operation Outreach gatherings, and Teen Escapes. Approximately 2,400 people were reached in 42 visits to Plasma Centers.

However, it’s not just patient gatherings that solidify the IDF success story; our medical outreach programs included nine LeBien Visiting Professor Programs and connected with more than 4,750 participants at 19 medical meetings, including the more than 3,600 that visited the IDF exhibit booth at six medical conferences.

Still, IDF’s influence reaches well beyond patient meetings and medical outreach. Through public policy action and advocacy, the Foundation is a strong and influential voice on the issues affecting our community and our quality of life.

Last year, IDF’s public policy efforts resulted in a Advocacy Day on Capitol Hill that saw our community meet with 120 members of Congress. There were 11 separate “action alerts” that were not only delivered to more than 40,000 people, but generated more than 7,500 letters to Congress.

IDF’s patient advocacy services benefited more than 8,000 patients and families seeking information and assistance, and we saw more than 3,000 patients participate in eight IDF surveys.

And, as the adage ‘if a tree falls in the forest’ intones, the breadth and effectiveness of all IDF events and programs would only be half as effectual if we fell short in communicating that information. IDF communications enlighten and inform our community with a thrice-yearly newsletter, circulation of 20,000, a monthly e-newsletter, which reaches 11,000, and a Website that attracts 15,000 unique visitors per month. And our social networking sites, IDF Friends and IDF Common Ground, which debuted last summer, have over 1,500 members.

Do numbers tell the whole story? Absolutely not, but when used as a gauge to measure both where our community has been and the direction in which we are headed, the realization of the goals of our mission statement are accelerating each and every day.
The basis for the campaign couldn’t have been any more straightforward. In medical schools, most doctors learn the saying, “When you hear hoof beats, think horses, not zebras.” In simpler terms, most physicians are taught to focus on the most likely possibilities when making a diagnosis, not the unusual ones.

But, as any patient with primary immunodeficiency knows, the aphorism does not apply to the diagnosis of PIDD. More often than not, delayed or missed diagnoses in patients with PIDD can lead to expanded health issues.

Thankfully, immunologists expect to see zebras.

Never did those words ring truer than in 2009, when scores of IDF volunteers embraced the primary immunodeficiency community with time, energy, talent and kindness.

More than 20 new volunteers joined the ranks of the 200 specially trained people who generously give of themselves to serve the needs of patients and family members. In 500 instances, peer support volunteers assisted first-time callers and devoted hours upon hours monitoring IDF’s online discussion forums.

The IDF volunteer network coordinated 30 support groups and educational meetings; greeted attendees and introduced presenters at the IDF 2009 National Conference. They coordinated 17 fundraising events and spoke to more than 2,300 people about IDF and PIDD at 41 Plasma Centers during “Blue Jeans for Healthy Genes” programs. Hundreds of IDF volunteers were also active in advocacy efforts, tirelessly supporting the PIDD community through the public policy arena. Volunteers help spread awareness of primary immunodeficiency in their communities throughout the United States.

IDF salutes all our volunteers and appreciates the amazing work they do to further our mission.
Patient Services

IDF’s declaration that we are a patient-driven, service-based organization was substantiated through action in 2009. IDF, along with our dedicated volunteer network, initiated more than three-dozen support group and patient education meetings last year.

The highly successful, local patient education meetings and Operation Outreach events are the perfect settings for patients and families to benefit from sessions presented by local immunologists and allergists who address the treatment and management of PIDD. Often there are presentations by insurance reimbursement specialists offering advice and resources, and pharmacists and physicians speaking on immunoglobulin therapy. Participants also receive an introduction to IDF, share in the knowledge and experiences offered by the Foundation’s Volunteer Support Network.

Nearly 900 IDF community members in nearly 20 states attended educational and support meetings in 2009.

The period of transition from adolescence to adulthood is a difficult time for most individuals; however, those affected by primary immunodeficiency diseases have an even more complicated time. IDF has long had an interest in developing age-appropriate programs and resources for teens and young adults and in 2009, IDF created the IDF Teen and Young Adult Program.

Three teen programs enjoyed a place of prominence in 2009, and nearly 130 youthful members of the IDF community attended Teen Escape events in Houston, Baltimore and Disney World.

The Eric Marder Scholarship Program of the Immune Deficiency Foundation awarded 35 scholarships to undergraduate students living with primary immunodeficiency diseases. The scholarships, totaling more than $31,000, are made possible by donations to a fund created in memory of Eric Marder, a young man who lost his battle with Common Variable Immune Deficiency.

The second edition of the “IDF School Guide, Information about Students with Primary Immunodeficiency Diseases” was published in 2009, offering updated and expanded information, for parents wanting information to help their children succeed in academic settings. This guide has proved to be a valuable reference throughout the school year.

Patient Advocacy Efforts - You can count on us

The numbers behind the IDF patient advocacy efforts reveal a telling statistic—there is an astounding increase in need for information and services from the primary immunodeficiency community. Over 8,000 people contacted IDF seeking answers and information in 2009.

When categorized, the largest percentage of inquirers, 2,700 requests, were seeking information on patient education. This was followed by questions on three health insurance categories: uninsured/underinsured questions, increased 123% over last year, the cost shifting/sharing of private health insurance went up 30% and insurance companies questioning the use of immunoglobulin (Ig) sky rocketed 43%.

In fact, when IDF investigated the sudden upturn in Ig-based denials, we found that either insurers often were no longer considering the treatment as medically necessary or they considered Ig investigational or experimental. As a result, an assistance tool “IDF Health Insurance Immunoglobulin Denials” was developed and added to our Website, where visitors can find tips and suggestions on how to appeal such denials.

Diagnosis questions also saw a significant increase – up 63 percent – leading us to believe that not only are more people being diagnosed, but they are also becoming increasingly aware that IDF will be there to answer their questions.
IDF 2009 National Conference — Record Numbers in Attendance

It happens just once every two years, but when folks gather for the Immune Deficiency Foundation’s National Conference all can have a good time, and unequaled educational experience!

If the inventive sessions, lively exhibit hall and invigorating special events didn’t offer a big enough enticement, the IDF 2009 National Conference had the backdrop of the Disney Contemporary Resort and Disney World to sweeten the temptation.

For three days, a record number of attendees, nearly 1,400, descended on the popular vacation destination for breakfast symposiums, panel discussions and comprehensive seminars that focused on healthcare and life management, public policy issues, IDF survey findings, and all things relative to members of the primary immunodeficiency community.

While days were spent attending educational programs – led by notable immunologists and experts – the attendees made sure to set aside some play time.

From a Teen Escape that included a scavenger hunt throughout the Magic Kingdom to the "Silly ‘Lympics" competitions to visiting the interactive Disney Quest theme park, Children from six months to 17 were able to enjoy the 2009 National Conference.

Adult attendees also had plenty of opportunities to ‘cut loose’ at the THINK ZEBRA! Celebration which featured a special evening of dinner, music and a silent auction where black and white stripes could be seen everywhere. A trip to the international venue of Epcot marked the close of the festivities, for a rousing firework spectacular.

Thanks to our generous conference sponsors, Baxter Healthcare, CSL Behring, Grifols, IgG America/ASD Healthcare, and Talecris Biotherapeutics, and everyone involved, the IDF 2009 National Conference was a ‘Celebration of Our Community’ the record number of attendees wouldn’t soon forget.
Grassroots Public Advocacy —
Strength in Numbers

As with any patient organization, IDF’s public policy involvement allows us to help shape public policies that affect our patients, families, industries and medical professionals. IDF works with state and national lawmakers and government agencies to influence policy and legislation.

As such, IDF was instrumental in the introduction of Senate Bill 701 (and its House companion bill – HR 2002), the Medicare Patient IVIG Access Act of 2009. Both bills, if passed, fix the problem of Medicare not paying for IVIG in the home setting as well as give the Secretary of Health and Human Services the power to deal with IVIG reimbursement issues. The Senate bill was introduced as nearly 50 members of the IDF community descended upon Capitol Hill to meet with 120 members of Congress on IDF’s annual Advocacy Day; both bills received bipartisan support.

There were 11 separate “action alerts” that were not only delivered to more than 40,000 people, but also generated more than 7,500 letters to Congress.

Health care reform legislation took center stage in the public policy debate, and IDF led the development of the Plasma Users Coalition’s (PUC) Principles for Health Care Reform. The Foundation was a regular participant in Families USA conference calls on health care reform legislation, and in coalition with 37 other organizations, lent our support to the elimination of lifetime and annual insurance limits on insurance coverage, which became law.

On the state level, IDF teamed with Alpha-1 and the Plasma Protein Therapeutics Association (PPTA) in Minnesota to encourage the introduction of and the passage of legislation that would require the state board of Pharmacy develop rules of provision of pharmacy services for PIDD, Alpha-1 and von Willebrand disease.

A new Advocacy Center Page was developed for the Foundation’s Website. In addition to two blogs and news stories, the page also features the Advocacy Channel, where filmed interviews pertaining to public policy issues can be viewed.

IDF SCID Initiative

Driven by requests from the Severe Combined Immune Deficiency (SCID) community, IDF unveiled the IDF SCID Initiative, a dedicated fund and project committed to supporting SCID specific programs such as education, awareness, diagnosis, newborn screening and the search for a cure.

Patients with SCID, commonly known as bubble boy disease, lack T lymphocytes; the white blood cells that help resist infections due to a wide array of viruses, bacteria and fungi. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive.

The mission of the IDF SCID Initiative is four-fold: expand awareness of SCID and the treatment options; increase early detection and treatment, with the goal to have universal newborn screening nationwide; fund research efforts that will identify new treatments, therapies, and ultimately a cure for SCID; and provide opportunities for affected individuals and families to attend educational events.

IDF has developed an oversight committee for the SCID Initiative fund, comprised of community members with specialized interest and knowledge specific of SCID

In 2009, the IDF SCID Initiative, together with the SCID Angels for Life Foundation and SCID.net, conducted a survey of SCID families. The results of this landmark survey were presented by Marcia Boyle when she testified before the Advisory Committee on Heritable Disorders and Newborns in Children in support of newborn screening.
Social Networking — Connecting the Community 24/7

Always on the leading edge of community involvement, IDF became one of the first patient organizations to pioneer the use of social networking for the benefit of the IDF community. Our social media initiative offers an open, engaging and fun environment where patients and families can share not only their experiences, but also the hopes and challenges that accompany living with primary immunodeficiency disease.

The anchor is IDF Friends, a social network created exclusively for the primary immunodeficiency community. IDF Friends helps patients and loved ones find and connect with members of the PIDD community and share common traits, interests and causes. IDF Friends members, 1,300 strong, engage with others with whom they may have traits or interests in common, and also participate in lively discussions.

IDF Common Ground has all the uniqueness of IDF Friends, but was developed specifically for teens and young adults with PIDD. It adds a younger slant to the online community, and provides its members with an opportunity to connect with peers who understand what it is like to live with PIDD.

The IDF Arcade, through games such as “Whack-a-Germ”, combines education and entertainment in order to teach young children about their disease.

The IDF Advocacy Channel – an online video channel - offers patient-generated videos explaining how current legislative or regulatory policies and actions are personally affecting patients or their families.

The IDF Reel Stories Channel chronicles patient-generated accounts of hope and inspiration, and serves as an outlet for a wide array of personal experiences, issues and topics. IDF encourages individuals to add their own testimonials, and to empower patients and families alike to tune in and share.

As demonstrated by the thousands of people currently active in our community, there’s no denying the societal role played by social networking in the 21st century. IDF is proud to have created online services that meet the needs of our ever-engaged community.

Professional Education

It was just a scant two weeks into 2009 when the first of nine LeBien Visiting Professor Programs was presented – at Tulane University. This program sponsored by IDF and USIDNET, promotes improved knowledge about primary immunodeficiency disease, is held at teaching hospitals throughout North America and most often includes leading clinical immunologists presiding over educational activities.

This past year, the LeBien Visiting Professor program visited hospitals in nine different states, and were presented at such notable institutions as the Hershey Medical Center, the University of North Carolina Chapel Hill, the Medical College of Wisconsin, Morehouse School of Medicine, University of Tennessee, College of Medicine, St. Johns Hospital and Medical Center, University of Texas Medical School-Houston and the University of Iowa’s Children’s Hospital.

IDF staffed exhibits at six professional medical conferences. IDF offered educational resources at the American Academy of Allergy, Asthma and Immunology, the Infusion Nurses Society, the National Association of School Nurses, the American Academy of Family Physicians, the American Academy of Pediatrics, and at the meeting of the American Autoimmune Related Diseases Association.

The publication “IDF Diagnostic and Clinical Care Guidelines” saw a revision in 2009 with the release of its second edition. In addition to the essential information drawn from the first edition, the second includes recommendations, strategies and indispensable information to assist physicians in making educated decisions about the appropriate health care of primary immunodeficiencies. It also features information that provides patients with the resources to deal more effectively with their physicians and with insurance providers.

The IDF Consulting Immunologist Program, a physician-to-physician service that provides a free second opinion or consult on primary immunodeficiency diseases, received and assisted 72 consult requests in 2009.

The IDF Nurse Advisory Committee created a Bill of Rights for Patients with a Primary Immunodeficiency Disease. This document stresses the privileges to which patients are entitled and deserve as well as the key role patients play in staying healthy by laying out their rights and responsibilities.
Survey Research — By the Numbers

Seeking feedback from primary immunodeficiency patients, health care professionals and medical associations reached new dimensions in 2009, as the IDF Survey Research Center embarked on more than 20 data-gathering projects designed to better serve the needs of our community.

The first national survey of Severe Combined Immunodeficiency Disease (SCID) provided survey results to support the testimony of IDF president Marcia Boyle when she testified before the Advisory Committee on Heritable Disorders and Newborns in Children. IDF expanded its position as a key, authoritative resource of information for the medical, governmental and industrial communities by providing data for the 2009 American Academy of Pediatrics (AAP) National Meeting and a survey of the membership of the American Academy of Family Physicians (AAFP).

The AAFP survey revealed a noticeable ‘knowledge gap’ for family physicians’ recognition and diagnoses of primary immunodeficiency disease. Because of the survey, IDF is now hard at work developing educational and outreach programs for the AAFP National Conference, designed to decrease the time between symptom onset and diagnosis of PIDD.

The 2009 IDF Patient Survey marked the first time IDF used the Internet to conduct a large and comprehensive patient assessment.

The IDF Survey Research Center is appreciative of those in our community who took part in our 2009 surveys, and would like to encourage those with the opportunity to participate in future studies to take a moment and get involved.

The data obtained from these projects is not only used to directly support education, advocacy and research, but also allows the voices of the PIDD community to be heard loud and clear.
The United States Immunodeficiency Network, USIDNET, is a consortium of leading immunologists whose purpose is to advance knowledge in the field of PIDD. The network solicits, develops, evaluates and implements clinical research strategies to advance the detection, understanding, diagnosis and treatment of primary immunodeficiency diseases. The USIDNET contract is comprised of four main components: the national patient registry, a cell repository, educational and mentoring programs to attract and train new investigators, and research subcontracts for new investigators. It is administered by IDF and funded by the National Institute of Allergy and Infectious Diseases (NIAID), which is a component of the National Institutes of Health (NIH), an agency of the Department of Health and Human Services (DHHS).

In January 2009, the new USIDNET patient-consented registry went live, bringing 1,400 patients over from the old registry started by IDF in 1992. During 2009, over 1,000 new patients have been enrolled. In addition, 25 new medical institutions and private offices have been approved to consent and enter patients bringing that total to 36 sites.

At the IDF 2009 National Conference, USIDNET enrolled 82 patients and unveiled the new “Quality of Life” survey. Due to an overwhelmingly positive response to this survey, USIDNET began the process of programming the survey into the registry database to allow direct, relevant information collection.

In all, 2009 saw the number of patients participating in the registry surpass the 2,400 mark.

While the importance of expanding the registry is immeasurable, the use of the data collected – by the medical community – is equally significant. During a six-month span there were four database research queries approved and run on the registry.

Fundraising — Counting on YOU!

Over the past year, creative fundraising events generated tens of thousands of dollars to help improve the quality of life for primary immunodeficiency patients and their families.

From the “Blue Jeans for Healthy Genes”, events hosted by BioLife Plasma Services, CSL Plasma and Biomat USA, and Biotest Plasma Centers to the highly successful THINK ZEBRA! campaign to grassroots activities such as blood drives, baseball nights, wine tastings, fashion shows and golf outings, the IDF community rallied – with both a spirit of volunteerism and tremendous financial assistance – to help support its mission.

IDF Core Service Sponsors are dedicated partners that support IDF at the highest level. In 2009, they included Baxter Healthcare, CSL Behring, Grifols, IgG America / ASD Healthcare, Octapharma, and Talecris Biotherapeutics.

BioRx also supported IDF as a home healthcare sponsor. These sponsors make an enormous difference in the Foundation’s ability to plan and provide long-term resources. IDF greatly appreciates these devoted sponsors and their commitment to our mission.

Generous contributions received from personal gifts during seasonal appeals, memorial and honorary gifts and IDF’s benefactors, supporters and sponsors continued to demonstrate the IDF community understands the importance of giving.

These remarkable gifts enable IDF to provide the essential services, education, information and support that our community so richly deserves. Thank you all for your generosity!

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

**2010 IDF Core Service Sponsors:** Baxter Healthcare • Biotest Pharmaceuticals • CSL Behring
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