Why zebras?
In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras,” and are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra. Patients with primary immunodeficiency diseases are the zebras of the medical world. So IDF says THINK ZEBRA!
Having been a part of the Immune Deficiency Foundation for many years, we have witnessed the impact of the IDF community grow exponentially. It all begins, however, with the power of the individual. The individual who is diagnosed with a primary immunodeficiency disease and requests educational publications from IDF. The individual who wants to learn more about caring for patients receiving immunoglobulin and enrolls in the online course for nurses. The individual who knows how important it is to help others living with primary immunodeficiency and becomes an IDF Volunteer. The individual who recognizes the need for SCID Newborn Screening in their state and contacts legislators.

Over the past year, IDF has helped thousands of individuals make a difference in their own lives and the lives of others. We saw the power of the individual especially in advocacy. Members of our community relied on IDF to learn about the issues affecting those living with primary immunodeficiency, including the Medicare IVIG Access Act and SCID Newborn Screening, and IDF gave them the platform to have their voices heard. Our community was integral to the passing of the Medicare IVIG Access Act, signed into law by President Barack Obama in January 2013, creating a three-year demonstration project allowing for the payment of home infusion services for Medicare patients with primary immunodeficiency to be implemented within one year of its signing. From newborns to Medicare patients, IDF continues to give a voice to those who cannot advocate for themselves.

Together with our advocacy efforts, IDF provides vital programs and resources to individuals, families and healthcare providers, at little or no cost to them. Looking back on 2012, it is remarkable what the IDF community has accomplished. More than 12,000 people attended IDF educational presentations in 123 cities in 37 states. IDF’s patient advocacy services helped fill the need for over 4,300 requests from individuals and families seeking education, information and assistance. In fact more than 110,600 IDF educational materials were distributed in response to requests. The IDF website received an average of 19,000 monthly visits, and IDF social networking sites, IDF Friends and IDF Common Ground, grew to almost 3,500 members. We are reaching more and more individuals each day.

The IDF 2012 Annual Report encapsulates quite a successful year, and we appreciate the dedication of so many who made it possible. It was a year that affirmed the incredible power of the individual and, most importantly, the impact of the IDF community.

Sincerely,

John Seymour, PhD, LMFT
Chair, IDF Board of Trustees

Marcia Boyle
IDF President & Founder
Passing the Medicare IVIG Access Act

After passing by an overwhelming majority in the House and unanimously in the Senate in December 2012, President Obama signed the Medicare IVIG Access Act into law on January 10, 2013. Over the past 10 years, thousands of patients and family members made their voices heard in Congress by sending more than 25,000 letters and participating in over 500 meetings. If not for the unwavering spirit of the IDF community, the Medicare IVIG Access Act would not have been introduced and become law. This law creates a demonstration project supporting access to all products in all sites of care for Medicare beneficiaries with primary immunodeficiency diseases by addressing a problem in the Medicare law and allowing beneficiaries access to intravenous immunoglobulin (IVIG) in the home.

In 2012, four separate Federal level calls to actions were sent through the IDF Action Alert system on the Medicare IVIG Access Act generating 2,104 letters and calls to Policy Makers. On Advocacy Day 2012, our volunteers visited 91 offices to meet with their members of Congress about the Medicare IVIG Access Act.

When Representative Brady named Carol Ann Demaret, IDF and Marcia Boyle, IDF President & Founder, in his remarks on the floor of the House on December 19, 2012, the magnitude of the work of so many, for so long became clear: “I especially want to thank my constituent friend, Carol Ann Demaret, the mom of David, for her decades of hard work on behalf of these patients. And I appreciate so much Marcia Boyle, the founder of the Immune Deficiency Foundation, and all those patients who for years have come up here asking for this help and change. Today, this Congress, Republicans and Democrats alike, join together in providing that help and that access.”
2012 Year in Review

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

Our mission statement, affirming our dedicated objective to improve diagnosis, treatment and quality of life for persons with primary immunodeficiency diseases, describes the basic goals of IDF. As we reflect on the past year, it is always helpful to review the statistics behind our ongoing programs and activities to evaluate the impact IDF had while working on behalf of our community in 2012.

Patient Services
As a national patient organization, education is central to our mission and each year, IDF hosts patient education meetings throughout the country. IDF believes it is imperative to increase efforts to partner with physicians in geographic regions to reach more patients and enhance the content of the meetings.

Patient Education Programs
In 2012, IDF hosted 20 Patient Education Meetings, which are daylong meetings where local experts present medical and life management sessions to adults. We also had three Family Conference Days, which are Patient Education Meetings with the addition of a youth program for ages 5 and up. Through these meetings, we project reaching approximately 1,480 people.

IDF Retreats are weekend gatherings for those living with primary immunodeficiency and give our community the unique opportunity to connect with other patients and family members. In 2012, two IDF Retreats were held in Milwaukee and Houston, drawing more than 200 attendees from 33 states and Canada. More than half were first time attendees, affirming that we are reaching more and more people, and those who we have met before continue to attend and benefit from our events.

IDF Teen Program
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. The IDF Teen Program contains many elements and ways to reach teens in the best ways possible. Throughout all the components are opportunities for teens to develop into strong, capable individuals.

Training is offered to leading teen volunteers on the IDF Teen and Young Adult Council. Members provide support at various IDF programs and interact with other teens on IDF Common Ground, www.idfcommonground.org, the social network exclusively created for teens living with PI where they can connect, share ideas and support one another.

IDF Teen Escape Weekends
IDF Teen Escape weekends are a central part of the teen program. Teens learn from healthcare and life management experts, mentors and peers, and issues they face are tackled and confidence is gained.

In 2012, IDF Teen Escape was held in Blue Ash, OH and was attended by 25 teens and young adults (ages 12 – 22) along with 30 parents.
IDF Academic Scholarship Programs
IDF awards scholarships to undergraduate students living with primary immunodeficiency diseases who plan on completing their post-secondary education. The Eric Marder Scholarship Program is open to patients with a primary immunodeficiency as classified by the World Health Organization and is intended for undergraduate students attending or entering college or a technical training school. The Varun Bhaskaran (WAS) Scholarship Program is open to undergraduate or graduate students living with Wiskott-Aldrich Syndrome (WAS).

For the 2011-2012 school year, 38 scholarships were awarded through the Eric Marder Scholarship Program, totaling $35,000. The Varun Bhaskaran Scholarship Program awarded one scholarship in the amount of $1,000.

Patient Advocacy
IDF assists patients and families with a broad array of services, including inquiries related to diagnosis, treatment, health insurance, peer support and literature requests. In 2012 more than 4,300 people contacted IDF seeking answers and information. When categorized, the largest percentage of inquirers, 2,343 requests, were seeking information on patient education. This was followed by questions related to insurance, including co-pay assistance, premium assistance, Medicare, Medicaid, insurance treatment denials and general insurance issues. In 2012, to streamline how we communicate about health insurance, we created a central page on our website, the Patient Insurance Center, with multiple graphics and links, designed to assist users in easily finding health insurance related information, programs, FAQ's and resources.

Requests also included locating a specialist, seeking peer support, medical/treatment questions and more. There was a considerable increase for requests for locating a specialist in 2012. In fact, compared to 2011 when there were 584 requests to find a physician that number jumped to 724 in 2012.

To encourage more people to contact IDF with their questions, in 2012 we added a prominent “Ask IDF” graphic to the header section of the IDF website, appearing on all pages. The graphic clearly directs patients to the page with the form through which users can submit questions and request materials.

IDF eHealthRecord
The IDF eHealthRecord is an electronic personal health record specifically developed for individuals and families living with primary immunodeficiency diseases. It allows users to safely store all their health information in one place and to easily print and share their information. It can be conveniently accessed from a computer, tablet or smartphone. The IDF eHealthRecord can help users keep track of medications, supplements, diagnoses, infections, symptoms, infusions, medical visits and medical history. IDF staff can provide personalized assistance to users if needed. In 2012 the IDF eHealthRecord saw system wide updates resulting in 375 new accounts, making a total of 735 accounts since product launch in July 2011.
IDF Volunteer Network

IDF has a nationwide network of dedicated volunteers committed to increasing awareness of primary immunodeficiencies in local communities. Many serve as peer support volunteers to offer encouragement and understanding to others as they live with a primary immunodeficiency disease. Others provide information on local resources, host educational meetings, advocate for public policy, and often organize fundraising events throughout the country.

In 2012, more than 100 volunteers, including patients and family members living with primary immunodeficiency, gathered for the IDF Volunteer Leadership Conference in Raleigh, NC to learn more about IDF and about their responsibilities as volunteers. It was calculated that the group had devoted a combined 784 years to IDF.

Throughout the year, peer support volunteers offered encouragement and advice for 256 patients or family members living with PI. Volunteer also significantly contributed to our advocacy and fundraising efforts, making them absolutely vital to IDF’s mission.

IDF Plasma Center Partners Program

The IDF Plasma Center Partners Program creates awareness about primary immunodeficiency diseases and shows the intertwined relationship between patients, plasma donors and employees in plasma collection centers throughout the U.S. IDF arranges plasma center visits for patients and family members where they can gain a better understanding of the importance of plasma donation. Often they are the first patient or family member who lives with a primary immunodeficiency that the center staff or plasma donors have ever met. By hearing their stories, the donors and employees better understand the lifesaving role they play in the lives of patients through the plasma collection process. The companies that participate in the IDF Plasma Center Partners Program help raise funds and awareness for IDF.

In 2012, our volunteer network helped spread awareness by distributing thousands of pieces of educational materials and spoke to approximately 4,800 people during 96 visits to plasma centers. In addition, we developed a section of our website for the IDF Plasma Center Partners Program and began featuring stories about the program in our blog.

Healthcare Professional Outreach

IDF fosters a supportive environment for groundbreaking continuing medical education to improve the diagnosis, treatment and care of primary immunodeficiency diseases. IDF programs and publications for healthcare professionals promote the recognition and management of primary immunodeficiency diseases.

IDF Medical Advisory Committee

The IDF Medical Advisory Committee (MAC) is comprised of prominent immunologists from throughout the country to support the mission of the IDF through the development of science based standards for diagnosis and care for individuals with primary immunodeficiency diseases. In 2012, members of the MAC attended IDF Patient Education Meetings and Retreats. They contributed to IDF publications, including the development of the IDF Patient & Family Handbook – 5th Edition, which was published in 2013. In addition members of the MAC helped answer questions from patients, families and healthcare professionals.

IDF Nurse Advisory Committee

The IDF Nurse Advisory Committee (NAC) works to improve the quality of healthcare and education provided by nurses for patients with primary immunodeficiency diseases and to increase awareness of primary immunodeficiency diseases through professional education and outreach. In 2012, the NAC launched a number of innovative projects that will help improve the quality of healthcare and education provided by nurses for patients with primary immunodeficiency diseases here in the U.S. and internationally.

The IDF Guide for Nurses Immunoglobulin Therapy for Primary Immunodeficiency Diseases –3rd Edition, published in 2012, includes general information about primary immunodeficiency diseases, delivery of Ig replacement therapy, product selection and characteristics, troubleshooting subcutaneous immunoglobulin therapy (SCIG) and more. The sleek design and pocket size make it easy to use for busy nurses.

Nursing Guidelines for Administration of Immunoglobulin Replacement Therapy is a comprehensive review of standards for administration of Ig therapy, developed by members of the IDF Nurse Advisory Committee. The guidelines were completed in 2012 and published in the January/February 2013 issue of The Journal of Infusion Nursing (Indexed in MEDLINE, CINAHL Plus, PubMed). This document is the first of its kind to offer infusion nurses solid guidelines on the standard of care in Ig administration.

In 2012 the IDF Nurse Advisory Committee released the IDF Video Series for Nurses in French, German and Spanish. The video series is based on the IDF Online Continuing
Education Course for Nurses: Primary Immunodeficiency Diseases and Immunoglobulin Therapy, which is a free, 5-hour, U.S. accredited course for nurses, written and recorded by committee. The course provides an update on primary immunodeficiency diseases, immunoglobulin (Ig) therapies and the nurse’s role with these therapies. The video series are free, non-credit translations of the course in French, German and Spanish. This project has been one of the widest reaching education programs for nurses sponsored by IDF.

A member of the NAC also served as an editor of the IDF Patient & Family Handbook – 5th Edition, which was developed in 2012 and published in 2013.

The IDF Consulting Immunologist Program provides physicians the opportunity to consult with expert clinical immunologists about patient specific questions and obtain valuable diagnostic, treatment and disease management information. Created to serve the needs of physicians who have questions about their patients with PI, this physician-to-physician service has been available since 1998 and has provided hundreds of free consults to physicians.

IDF Consulting Immunologist Program provides second opinions or consults on issues of diagnosis, treatment and disease management. Patient issues range from interpreting laboratory testing to choosing appropriate medical therapies to working effectively with insurance company denials and questions. The consult might be about a newly diagnosed patient or someone who does not seem to fit any specific primary immunodeficiency diagnosis. All questions regarding patients are welcomed and requests are forwarded on to a skilled immunologist working with this program. In 2012, 79 physicians took advantage of this service. Currently, IDF has seven immunologists available as Consulting Immunologists.

In 2012, visiting professorships were held at Advocate Hope Children’s Hospital; Children’s Memorial Hospital, Chicago; Children’s Mercy Hospitals and Clinics/Univ of Missouri-Kansas City School of Medicine; Geisinger Health System; Mass General Hospital for Children; Miami Children’s Hospital; Quillen College of Medicine; and St. Luke’s Children’s Hospital. In 2012, 1,740 healthcare professionals were reached through the Visiting Professor Program.

Medical Meetings and Exhibits
IDF strives to increase visibility in the medical community by attending national medical conferences that generally include a booth in the exhibition hall. This allows staff to interact with physicians and other healthcare providers who see patients with PI, to discuss educational opportunities and to distribute educational literature and discuss IDF resources. In 2012 IDF exhibited at American Academy of Allergy, Asthma and Immunology, American Academy of Pediatrics, Clinical Immunology Society, Immunoglobulin Nursing Society, and Infusion Nurses Society.

IDF presented scientific posters for:
- American College of Allergy, Asthma and Immunology (ACAAI)
- Infusion Nursing Society (INS)
- International Nursing Group for Immunology (INGID)
- American Academy of Allergy, Asthma and Immunology (AAAAI)
- Immunoglobulin Nursing Society (IgNS)
- European Society for Immunodeficiencies (ESID)
- Primary Immunodeficiency Disease Treatment Consortium (PIDTC)

United States Immunodeficiency Network (USIDNET)
The United States Immunodeficiency Network (USIDNET) is a research consortium established to advance scientific research in the field of primary immunodeficiency diseases. The work of this consortium is funded by the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health (NIH). The role of USIDNET is to provide resources for work on the primary immunodeficiency diseases. These resources include the establishment and expansion of a Patient Registry, a program for the education and mentoring of young investigators and the maintenance of a Repository for cells for use in research. The goal of the Registry is to advance research in this field and to examine and improve the quality of life of patients; at present more than 3,300 patients have joined and medical data entered. For the mentoring resource, young physicians and fellows are given a number of opportunities to meet with and
learn from experienced investigators working in primary immunodeficiency, including the yearly intensive course in primary immunodeficiency diseases offered in conjunction with the Clinical Immunology Society. The Repository, managed by Coriell, now contains cell lines from patients with a variety of primary immunodeficiency diseases; these are made available to investigators who need these materials in their research.

IDF administers USIDNET, overseen by a steering committee of the leading clinical immunologists in the U.S. To increase awareness, informational brochures about USIDNET were published in 2012; one was targeted to patients and the other to healthcare professionals.

Public Policy and Advocacy
Through public policy action and advocacy, IDF strives to be a strong and influential voice on the issues affecting our community and our quality of life. Along with the passing of the Medicare IVIG Access Act, last year we made great strides in our public policy efforts. The IDF 2012 Advocacy Day on Capitol Hill saw our volunteers visit 91 offices to meet with their members of Congress about issues important to the primary immunodeficiency community. Nine separate Federal and State level calls to actions were sent through the IDF Action Alert system generating 3,479 letters and calls to Policy Makers.

Newborn Screening for Severe Combined Immune Deficiency (SCID)
SCID was once only identified after serious life-threatening infections. It can now be detected using the same dried blood spot that is used for other newborn screening tests. In 2010 SCID was added to the federal recommended universal screening panel thanks to the work and advocacy of the IDF community. Now the work remains to get this test added to the panel in all 50 states.

In 2012, volunteers working on the SCID newborn screening campaign were active in 21 states, including giving testimony to the legislature or advisory committees in 15 states. Four states were added in 2012: Connecticut, Florida, Mississippi and Texas. States currently screening for SCID: California, Colorado, Connecticut, Delaware, Florida, Iowa, Massachusetts, Michigan, Minnesota, Mississippi, New York, Ohio, Pennsylvania, Texas, Utah and Wisconsin. Territories screening: Navajo Nation. States currently planning to begin screening in 2013: Illinois, Oklahoma, Missouri, Nebraska, North Dakota, Rhode Island, South Dakota, Washington, West Virginia, Wyoming. States where Advisory Committees have approved adding SCID, but have a longer timetable for implementation: District of Columbia, Georgia, Maryland, Maine, North Carolina, New Jersey, Virginia.

In 2012, IDF published a helpful guide for parents who receive an abnormal screen called “Newborn Screening for Severe Combined Immunodeficiency (SCID) and Conditions Associated with T Cell Lymphopenia, A Guide for Parents Who Receive an Abnormal Screen.”

Healthcare Reform Implementation
With passage of the Affordable Care Act (healthcare reform law), IDF and fellow members of the American Plasma Users Coalition (A-PLUS) have worked together with the purposes of changing regulations as well as educating patients on implementation issues: submitting comments to Federal agencies, producing educational webinars and developing the IDF Health Insurance Toolkit to help patients find appropriate health insurance coverage. IDF also submitted comments on state exchanges advocating for inclusion of issues relevant for patients with PI and educated patients about implementation efforts and opportunities for advocacy at Patient Education Meetings and IDF Retreats.

Private Health Insurance
Over the past several years, the health insurance industry has increasingly been looking at the cost and increased usage of Immunoglobulin (Ig) as an issue and has devised various tactics to decrease Ig treatment costs at the expense and risk of patients.

Coventry Health Care created a single-brand formulary for Ig therapy that went into effect on December 1, 2011, restricting patients to not only one Ig product but also to exclusively administer intravenously and in the home setting. IDF launched a campaign emphasizing patient safety and the role of doctors in making treatment decisions sending letters and conducting phone calls with Coventry, developing InsurersAreNotDoctors.org to serve as a home for advocacy materials and campaign information and identifying patients with experiencing switching products who are covered by Coventry for media stories and inclusion in IDF publications and website.

As a result of the continued health insurance industry emphasis on reducing costs in a way that limits care, it was clear that IDF needed to educate the insurance industry about all aspects of PI. IDF developed and implemented the
Payer Policy Task Force, made up of stakeholders including representatives of the health insurance industry, which will proactively educate insurance companies about PI, Ig replacement therapy and other aspects of PI. The goal of the PPTF is the development of a consensus white paper that delineates guidelines and recommendations for standards of care ensuring patient safety and cost efficiencies as they relate to Ig therapy and the care of patients with primary immunodeficiency diseases.

Grassroots Advocacy
In 2010, IDF expanded the Action Alert program, our online advocacy tool on the IDF Website, to include not only Federal policymakers, but also those at the state level. Action Alerts have been very successful in mobilizing our community to raise awareness on critical issues. In 2012, IDF utilized the Action Alert system for four state level calls to action in response to proposed implementation of an Ig formulary, SCID newborn screening legislation and Health Care Reform Implementation. These were instrumental in campaigns that saw concessions to restrictive Ig policy and enactment of SCID legislation.

IDF filmed 4 new videos for the Advocacy Channel – Formulary issue with Coventry Healthcare, Medicare IVIG Access Act, Using the Media as an Advocacy Tool, SCID Newborn Screening in Texas – which were showcased in a new format with videos categorized by topic that has shown increased viewing metrics.

Survey Research
IDF national patient surveys provide crucial insight into the personal impact of primary immunodeficiencies and help the IDF develop policies for improved diagnosis and treatment. The major health surveys conducted by the government in the U.S., the National Health Interview Survey and the National Health and Nutrition Examination Survey, do not collect information on primary immunodeficiency diseases. As such, in 1995, IDF undertook the first national survey of the state of primary immunodeficiency diseases in the U.S. The only national estimates of the characteristics and experiences of patients with primary immunodeficiency diseases are from the three National Patient Surveys conducted by IDF in 1996, 2002 and again in 2007. In 2012, we conducted the 4th National Patient Survey along with six other important surveys. Overall, we saw more than 2,400 patients participate in the surveys.

Communications
In 2012 IDF communications continued to enlighten and inform our community with our newsletter, *IDF ADVOCATE*, published three times a year (circulation of 25,000), and a monthly e-newsletter, *Primary Immune Tribune*, (reaching over 14,500). Our website boasted a 47% increase in visits over 2011. Our social networking sites, IDF Friends and IDF Common Ground, grew to almost 3,500 members. Add to that, IDF maintained active blogs about news and events in the community as well as the IDF TV hub for all our videos, which have been watched 207,172 times. The new IDF Kids Connection section of our website houses the IDF Zebra Zone, IDF Arcade and other information for kids. The IDF Arcade, filled with educational games for children of all ages, has been visited 4,617 times.

IDF took advantage of external social media websites to promote programs and initiatives, and our numbers grew in 2012 with more than 3,600 facebook likes and 400 twitter followers.

IDF promoted National Primary Immunodeficiency Awareness Month in April. We provided volunteers with talking points on primary immunodeficiency, FAQ’s, IDF Information Sheet. We encouraged patients and family members to host their own awareness and fundraising events, and we promoted Awareness Month activities through our all of our communications, including our newsletter, e-newsletter, website, IDF Friends, IDF Common Ground, facebook and twitter.
Leadership

IDF Board of Trustees

John Seymour, PhD, LMFT - Chair
Barbara Ballard
Douglas R. Bell
John Boyle, PhD
Marcia Boyle
Joel Buckberg - Secretary
Rebecca H. Buckley, MD - Medical Advisory Committee Chair
Carol Ann Demaret
Steve Fietek - Vice Chair
Terry Halper
Mary Hurley
Chuck Lage
Robert LeBien
Richard Low, Jr.
John Smith
Amy Walsh

Front row, from left: Mary Hurley; Carol Ann Demaret; Marcia Boyle; Barbara Ballard; Rebecca H. Buckley, MD, Medical Advisory Committee Chair; Amy Walsh. Back row: John Seymour, PhD, LMFT, Chair; Steve Fietek, Vice Chair; Terry Halper; Richard Low, Jr.; John Smith; Chuck Lage; John Boyle, PhD; Robert LeBien; Joel Buckberg, Secretary. Not pictured: Douglas R. Bell.

IDF Staff Management Team

Marcia Boyle
President & Founder

Katherine Antilla
Vice President, Education and Volunteers

Christine Belser
Vice President, Programs and Communications

Lawrence A. LaMotte
Vice President, Public Policy

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Human Resources & Office Manager

Sarah Rose
Director of Finance
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National Institutes of Health

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National Jewish Medical and Research Center

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Miami Children’s Hospital

Steven Holland, MD
National Institutes of Health

Richard Hong, MD
Biomosaics

Howard M. Lederman MD, PhD
Johns Hopkins

Harry L. Malech, MD
National Institutes of Health

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All Seasons Allergy, Asthma & Immunology

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Seattle Children’s Hospital

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University of California, San Francisco

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Children’s Hospital of Wisconsin

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Texas Children’s Hospital

E. Richard Stiehm, MD
UCLA School of Medicine

Kathleen Sullivan, MD, PhD
Children’s Hospital of Philadelphia

Troy Torgerson, MD, PhD
Seattle Children’s Hospital

Jerry Winkelstein, MD

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Loris Aro, RN
Susman & Associates Immunology

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Midwest Immunology Clinic

Amy Meyer, RN, CPNP-PC
Children’s Hospitals & Clinics of Minnesota

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Texas Children’s Hospital

Jeanette Scott, BSN, RN

Debra Sedlak, CPNP
Duke University Medical Center

Gretchen Vaughn, RN, MSN, CPNP
All Children’s Hospital – St. Petersburg
Each year leading companies in the healthcare industry provide financial support to the IDF. Without such funding, IDF would be unable to provide our community with many of the services, resources and programs that contribute to the improved quality of life for the individuals and families of those living with primary immunodeficiency disease. IDF Core Service Sponsors are dedicated partners that support IDF at the highest level.

They help fund direct services, that offer peer support, help locate a specialist and offer information on dealing with health insurance issues. Local patient meetings and volunteer activities are also sponsored. They support medical and scientific programs like our Consulting Immunologist Program and the IDF & USIDNET LeBien Visiting Professor Program, as well as IDF exhibits at medical meetings.

IDF does not charge for membership. Funding from sponsors allows IDF to provide services and publications free of charge to our community. Our sponsors understand the chronic nature of these diseases. Because the diseases never go away, patients and their families will continually rely on IDF programs. IDF extends sincere appreciation to these companies for their continual support.

**2012 IDF Core Service Leaders**

Baxter Healthcare Corporation  
CSL Behring  
Grifols

**2012 IDF Core Service Supporters**

Biotest Pharmaceuticals  
IgG America / ASD Healthcare / US Bioservices  
Kedrion Biopharma  
Octapharma  
Sigma-Tau Pharmaceuticals

**2012 IDF Sustaining Contributor**

Walgreens – IG Therapy Program

**2012 IDF Sponsors**

Accredo  
BioFusion  
BioRx  
Coram  
InfuScience, a BioScrip Company
2012 Revenue of $5,838,423

- Contributions and Grants: $4,823,632 (82.62%)
- Government grants and other contract revenue: $148,530 (2.54%)
- Investment income: $34,098 (0.58%)
- Other income: $182,738 (3.13%)
- Special events: $649,425 (11.12%)

2012 Expenses of $4,604,215

- Medical and scientific: $2,795,084 (60.71%)
- Services to patients and families: $1,153,447 (25.05%)
- Administration and finance: $559,202 (12.15%)
- Marketing and fundraising: $96,482 (2.10%)
## Consolidated State of Activities
### Year Ended December 31, 2012

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<thead>
<tr>
<th>The Foundation</th>
<th>PIRC</th>
<th>Eliminations</th>
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<td><strong>Public support and revenue:</strong></td>
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<tr>
<td><strong>Public support:</strong></td>
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<td>Contributions and grants</td>
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<td><strong>Revenue:</strong></td>
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<td>Investment income</td>
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<tr>
<td>Other income</td>
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<td>Special events</td>
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<td><strong>Total revenue</strong></td>
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<td><strong>Total public support and revenue</strong></td>
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<td><strong>Expenses:</strong></td>
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<td>Program services:</td>
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<td>Medical and scientific</td>
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<td>Services to patients and families</td>
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<td>Supporting services:</td>
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<tr>
<td>Administration and finance</td>
<td>559,202</td>
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<tr>
<td>Marketing and fundraising</td>
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<tr>
<td><strong>Total expenses</strong></td>
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<td><strong>Change in unrestricted net assets</strong></td>
<td>830,062</td>
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<td><strong>Changes in temporarily restricted net assets:</strong></td>
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<tr>
<td>Corporate grants</td>
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<td>Interest and other income</td>
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<td>Net assets released from restrictions</td>
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<td><strong>Change in temporarily restricted net assets</strong></td>
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<td><strong>Changes in permanently restricted net assets:</strong></td>
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<td>Contributions</td>
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<td><strong>Change in net assets</strong></td>
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<td>(15,910)</td>
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## IDF and PIRC Total
### Statement of Functional Expenses - 2012

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<th>Services To Patients And Families</th>
<th>Total Program Services</th>
<th>Administration And Finance</th>
<th>Marketing And Fundraising</th>
<th>Total Supporting Services</th>
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<td>1,552</td>
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<td><strong>Payroll taxes, etc.</strong></td>
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<td><strong>Total salaries and related expenses</strong></td>
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<td>755</td>
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<td><strong>Total expenses before depreciation and amortization (including salaries)</strong></td>
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Cindy Yvanez
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<td>Melissa and Adam Freestone</td>
<td>Diana Gill</td>
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<td>Lynne and Thomas French</td>
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Lisa Goldberg
Sharon and Ira Goldman
Goldstein Valuation, LLC
Charlene Goren
Amy Grainger Baker
M. Phyllis and Robert Green
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Ronna Goldstein-Usmani
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Thelma Partridge
Kelly Patterson
Cheryl Pecknaphaugh
Allison and David Penn
Special Events
IDF is grateful to the members of our community who raised funds on IDF's behalf in 2012. Below are the event names and, if applicable, the organizers.

Bake Sale, Kim and Austin Farley
BJHG Fundraiser, Yvette Shorten
Blood Drive In Honor of Nicholas and Dylan Sutton, Lisa and Bryan Sutton
Cake Walk by Student Council In Honor of Anna Wojciechowski
Chinese Auction, Heather Gage
Jeans Friday Charity, Cemex, Inc.
Join the Herd! Legends Pub, Joanna Tierno
Fundraiser, Andrew Pic and Family
Fundraiser, Emma Bozarth
Fundraiser for IDF SCID Initiative, In Memory of Samantha Penn
IDF Run, Michael Jirsa
Illinois Patient Education Raffle, Amy Walsh and Zina Berryhill
Lia Sophia Jewelry Event, Amanda Davis and Jessica Brunner
Neighborhood Yard Sale and Bake Sale, Roger and Colleen Brock
Team Hope Beer Tasting, The Bush, Boddy, Fox, Rastad and Spinale Families
Team Hope 4th of July Event, The Bush, Boddy, Fox, Rastad and Spinale Families
THINK ZEBRA! Fundraiser, The Green Family
Turkey Trot, Marty and John Cowan
San Antonio Saddle Horse Association, Inc., Kendall and Laura Paris
Second Annual Bowling Fundraiser for IDF SCID Initiative, In Memory of Samantha Penn
Zebra Campaign, Kathy Mowen
Zumba for Zebras, Melody Medellin

IDF Plasma Center Partners Program
IDF appreciates the companies that participate in the IDF Plasma Center Partners Program and help raise funds and awareness for IDF. The support, enthusiasm and creativity of center employees along with the generosity of plasma donors has helped this valuable program develop from a few centers in 2005 to nearly 300 centers nationwide.

In 2012, the centers helped raise $128,964.71.
BioLife Plasma Services
Biomat USA
Biotest
CSL Plasma
Octapharma Plasma

The Immune Deficiency Foundation makes every effort to ensure the accuracy of donor lists. We extend our deepest regrets to any donor who may have been inadvertently omitted from this report. If you have a concern or correction, please contact us at 800-296-4433.