Why does IDF say THINK ZEBRA?

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!
As parents of children with primary immunodeficiency diseases, we know how difficult it can be finding information or guidance when a family member is diagnosed. When the Immune Deficiency Foundation (IDF) was founded in 1980, one of the main goals was to provide tools and resources to those living with primary immunodeficiency diseases (PI). It is with that same spirit and perspective that IDF exists today, thriving as a patient organization.

We are proud to relay that in 2013, IDF launched major initiatives that brought the IDF community together, provided new resources and helped patients and families advocate for themselves and take control of their lives.

**IDF 2013 National Conference**
IDF hosted one of the largest National Conferences in the Foundation's history in Baltimore, MD last June, with more than 1,200 people attending, including 44 states, Washington, DC, and twelve countries. Our National Conference is the world’s largest gathering of families affected by PI and offers exceptional opportunities. First, the largest delegation of the PI community ever, approximately 300 people, traveled from Baltimore to Capitol Hill for a historic IDF Advocacy Day. When the conference sessions began, participants of all ages gained skills to manage their health, while several first-time attendees experienced meeting other patients for the first time. All learned from experts in the fields of healthcare, life management, and other disciplines. Many who attended remarked that they left the conference empowered and prepared to better manage living with their PI.

At the National Conference, many new initiatives were launched, but in particular two essential resources were introduced. The *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases - 5th Edition*, the trusted publication featuring new chapters and the latest information about diagnosis, treatment and life management was given to attendees, along with other new publications. To satisfy the demands of our growing community and to stay current with the latest technologies, the IDF website, [www.primaryimmune.org](http://www.primaryimmune.org), was redesigned and audited. It is now mobile responsive with easy-to-use menus and additional content, including life stage sections.

**IDF Walk for Primary Immunodeficiency**
IDF launched a national walk program in 2013, IDF Walk for Primary Immunodeficiency. Many in our community have long asked how they can create awareness about PI and help IDF, and the walk program gives them the opportunity to do just that. Three walks were held in Philadelphia, Los Angeles, and Chicago and nearly 1,300 walkers participated. More than $430,000 was raised from walkers and sponsors. The response from the first year was extraordinary! There were teams of family and friends, teams of coworkers, teams of classmates. Patients and families living with PI really reached out and rallied those closest to them. We were truly inspired by the generosity and enthusiasm of our community, and we are extremely grateful to our walkers and sponsors. IDF Walk for Primary Immunodeficiency is undoubtedly a game-changer for the PI community—it’s a way for our community to make a lasting impact.

**PI CONNECT**
As the year came to a close, we received wonderful news. In December 2013, IDF was approved for a funding award for PI CONNECT from the Patient-Centered Outcomes Research Institute (PCORI). We were thrilled! IDF was one of only 29 recipients and the selection was very competitive. We were so honored to have IDF recognized for its expertise, resources and commitment to engaging patients.

PI CONNECT will be part of PCORnet: the National Patient-Centered National Clinical Research Network. This network aims to advance the shift in clinical research to patient-centered studies, giving patients “a seat at the research table.” Our PI CONNECT will be part of a secure, national data network that improves the speed, efficiency, and use of patient-centered comparative effectiveness research to boost the efficiency of health research. PI CONNECT will build upon our existing programs supported by our motivated patient community who want results.

It is hard to only focus on three of our achievements when there were so many accomplishments during the year. Please review this Annual Report 2013 that captures an incredible year during which IDF continued to be the authoritative source for the PI community, providing patients and family members with vital tools to help them improve their lives. We appreciate the hard work and dedication of so many who made it possible.

Sincerely,

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

Marcia Boyle
IDF President & Founder
2013 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.

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 2013.

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 healthcare professionals in geographic regions to reach more patients and enhance the content of the meetings.

Patient Education Programs
In 2013, IDF hosted 20 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 Education Meetings with the addition of a youth program for ages 5 and up. Through these meetings, we reached 1,294 people.

IDF 2013 National Conference
The IDF 2013 National Conference, held June 25-27, 2013 in Baltimore, MD, provided hundreds living with PI the opportunity to learn more about the disorders, to discover ways to manage their health, and to connect with others who understand. More than 1,200 people of all ages traveled from all over the world, including 44 states, Guam, France, South Africa, the United Kingdom, Canada, Italy, Germany, Australia, Israel, Belgium and Argentina. It all began with IDF Advocacy Day on Thursday, June 27. Approximately 300 people traveled to Washington, D.C. to advocate for needs of our community—this was the largest delegation of the PI community on Capitol Hill ever. They met with Members of Congress for personal meetings throughout the day.

Later that day, everyone returned to Baltimore for the Welcome Reception officially kicking off the conference, featuring a performance of the national anthem and an Armed Forces Color Guard. Over the next two days, 53 healthcare and life management experts conducted nearly 40 presentations that provided vital information to patients and families. Speakers discussed advancements in diagnosis and treatments as well as topics related to living with PI, like autoimmunity, allergies, mental health, parenting skills, employment, health insurance and more. “All of the speakers presented their topics in a manner which was easy to understand for non-clinicians," said one attendee. “This was my first conference. I intend to make it the first of many.”
Children, tweens and teens participated in age appropriate, educational activities during the IDF Youth Program. Parents were thankful for the experiences of their children. A mother of a patient explained, “The experience of meeting other children that have the same diagnosis as my son with CVID was priceless for him.”

Another mother said, “Thank you for helping our children become better educated about their disease. You have made our lives easier and better because we have the knowledge and understanding of primary immunodeficiency.”

At the end of each day, everyone had a chance to relax with special celebrations. Friday’s Stars and Zebra Stripes Gala included the THINK ZEBRA! Silent Auction, musical entertainment and an awards presentation. Family fun was had by all at Saturday’s IDF Night at the National Aquarium in Baltimore.

The IDF 2013 National Conference was a tremendous success, educating patients and families and bringing together so many members of the community. “This was the most amazing and positive experience,” said one patient, “I will be recommending this to anyone with primary immunodeficiency … You put together an experience that was so affirming for us.”

The IDF 2015 National Conference, the eighth national conference, will take place at the Hyatt Regency New Orleans on June 25-27, 2015.

The Boyle Scientific Achievement Award
At the IDF 2013 National Conference, Michael S. Hershfield, MD received The Boyle Scientific Achievement Award. Established by IDF in 1992, this award pays tribute to a member of the medical/scientific community who has extensively contributed toward improving the diagnosis and care of patients with primary immunodeficiency diseases.

Dr. Hershfield is a professor of medicine and biochemistry at Duke University Medical Center in Durham, NC. He has authored or coauthored nearly 100 research articles and case reports related to PI. Dr. Hershfield has also sparked collaboration with an international group of pediatric immunologists in efforts to reach a consensus on optimal therapy for patients with Severe Combined Immune Deficiency (SCID) and other specific types of PI.

“For more than two decades, Dr. Hershfield’s pioneering research efforts and generous donation of his expertise and laboratory testing of SCID blood samples have provided a vital global resource for diagnosing and treating ADA-deficient SCID and ruling it out in the others,” said Rebecca Buckley, MD, Professor of Pediatrics and Professor of Immunology at Duke University Medical Center and Chair of the IDF Medical Advisory Committee. “We are confident Dr. Hershfield’s dedication to primary immunodeficiency will inspire other physicians and researchers by showing how scientific achievement can directly impact patients and lead to a better quality of life for people with these diseases.”

IDF Achievement Award
Carol Ann Demaret, a long time IDF Board member, received the IDF Achievement Award at the IDF 2013 National Conference for her work on
behalf of the PI community. Carol Ann’s son David Vetter, affectionately known as the boy in the bubble, was born with SCID.

Carol Ann has been an active and devoted member of the IDF Board of Trustees since 1992. “She has never turned down a request to assist in our mission,” explains IDF President & Founder Marcia Boyle, “She has given testimony to Congress and in her state on a number of issues, ranging from SCID Newborn Screening, Medicare access to IVIG.” Whenever given the opportunity, she works to raise awareness of primary immunodeficiency. IDF has worked for many years on the Medicare IVIG Access Act, which was signed into law by the President on January 10, 2013.

This law was the result of advocacy from the whole community, but Carol Ann holds a special place in its success. U.S. Representative Kevin Brady (R-TX) was our lead champion in Congress because of his constituent, Carol Ann. Representative Brady actually thanked her in his remarks on the floor of the U.S. House of Representatives on H.R. 1845, the Medicare IVIG Access Act, December 19, 2012.

IDF Teen Program

The period of transition from adolescence to adulthood is a difficult time for most individuals; however, those affected by PI 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 teen volunteers on the IDF Teen Council. 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, ages 12 – 18, learn from healthcare and life management experts, mentors and peers, and issues they face are tackled and confidence is gained. Meanwhile, parents participate in sessions geared toward their own issues and concerns.

In 2013, IDF Teen Escape weekends were held in and Dallas, TX, Needham, MA, and Orlando, FL. In total, 238 people attended the weekends in 2013.
IDF Volunteer Network
IDF has a nationwide network of dedicated volunteers committed to increasing awareness of PI in local communities. Many serve as peer support volunteers to offer encouragement and understanding to others as they live with PI. Others provide information on local resources, host educational meetings, advocate for public policy, organize fundraising events and support the IDF Walk for PI.

In 2013, peer support volunteers offered personalized encouragement and advice to 263 patients or family members living with PI in addition to spending thousands of hours supporting others at IDF Friends.

IDF Plasma Partners Program
The IDF Plasma Partners Program creates awareness about PI 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 PI 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 Partners Program help raise funds and awareness for IDF. In 2013, our volunteer network helped spread awareness by distributing thousands of pieces of educational materials and spoke to approximately 3,500 people during 70 visits to plasma centers.

Volunteers also significantly contributed to our advocacy and fundraising efforts, making them absolutely vital to IDF’s mission. Overall, thousands of volunteer hours are donated to IDF each year!

IDF appreciates the companies that participate in the IDF Plasma 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 2013, the centers helped raise $145,377.00. Thank you to Biotest, CSL Plasma and Grifols for their participation.

IDF Academic Scholarship Programs
IDF awards scholarships to undergraduate students living with PI who plan on completing their post-secondary education. The Eric Marder Scholarship Program is open to patients with a PI 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 2012-2013 school year, 55 scholarships were awarded through the Eric Marder Scholarship Program, totaling $40,000. The Varun Bhaskaran Scholarship Program awarded two scholarships in the amount of $1,000 each.

Patient Advocacy Program
In 2013, IDF’s patient advocacy services helped fill the need for over 5,200 requests from patients and families seeking education, information and assistance. We assist patients with PI with a broad array of services including inquiries related to diagnosis, treatment, health insurance, peer support and literature requests.

The top three reasons that patients call IDF are for: (1) education, (2) assistance in dealing with the many health insurance problems that they encounter and (3) assistance in locating an immunologist in their area.

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 2013, members of the MAC presented at IDF local Patient Education Meetings and at the 2015 National Conference. They contributed to IDF publications, including the development of the IDF Patient & Family Handbook – 5th Edition and Clinical Focus on Chronic Granulomatous Disease, which were published in 2013. Members played valuable roles...
with health insurance issues that concern our patients. In addition, members of the MAC help answer questions from patients, families and healthcare professionals throughout the year.

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 2013, the NAC participate in innovative projects that will help improve the quality of healthcare and education provided by nurses for patients with PI here in the U.S. and internationally. NAC members present at patient meetings, contribute to IDF publications and help answer questions received from patients.

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 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.

IDF and USIDNET LeBien Visiting Professor Program
The IDF and USIDNET LeBien Visiting Professor Program promotes improved knowledge about the diagnosis and treatment of PI. Teaching hospitals throughout North America may request a leading clinical immunologist to lead Grand Rounds or present at other educational activities, such as bedside rounds or house staff and/or medical residents conferences. This program is available at no cost to the participating hospital.

In 2013, visiting professorships were held at Children’s Mercy Hospital, Children’s Memorial Hospital, William Beaumont Hospital, SUNY Downstate Medical Center, St. Francis Hospital and Medical Center and Stony Brook Children’s Hospital. In 2013, 1,040 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 2013 IDF exhibited at American Academy of Allergy, Asthma and Immunology, American College of Allergy, Asthma and Immunology, Immunoglobulin Nursing Society, and Infusion Nurses Society.

IDF presented scientific posters for:
- American Academy of Allergy, Asthma and Immunology (AAAAI)
- Association of Public Health Laboratories (APHL)

PI CONNECT
IDF Patient-Powered Research Network, Bringing Together IDF ePHR and USIDNET
In December 2013, IDF was approved for a funding award for PI CONNECT, the new IDF Patient-Powered Research Network, from the Patient-Centered Outcomes Research Institute (PCORI). PI CONNECT will be part of PCORnet: the National Patient-Centered National Clinical Research Network. PCORnet aims to advance the shift in clinical research to patient-centered studies, giving patients “a seat at the research table.” PCORI envisions PCORnet to be a secure, national data network that improves the speed, efficiency and use of patient-centered comparative effectiveness research.

PI CONNECT connects the information patients enter in their IDF ePHR, the online personal health record for patients with PI (formerly known as the IDF eHealthRecord) with the United States Immunodeficiency Network (USIDNET) patient-consented registry, which contains clinical data on several thousand patients with PI. Bringing together this information through PI CONNECT gives researchers a better idea of the patient experience. PI CONNECT along with all networks in PCORnet will form a new national resource that aims to boost the efficiency of health research. PI CONNECT will launch in September 2014.
IDF ePHR (Previously IDF eHealthRecord)

The IDF ePHR is the electronic personal health record specifically developed for individuals and families living with PI. At the end of 2013, there were 1,089 accounts. To enhance the user experience and overall functionality, IDF ePHR will be redesigned and built on an entirely new system in 2014. Currently the system 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. It 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.

Taking all the helpful features found in the original IDF eHealthRecord, the new IDF ePHR will add convenient tools to help patients live healthier lives. This one central location will offer the latest advancements in health record system management. In 2014, upon registration, IDF ePHR users will have the opportunity to consent into PI CONNECT and USIDNET.

United States Immunodeficiency Network (USIDNET)

The United States Immunodeficiency Network (USIDNET) is a research consortium established to advance scientific research in the field of PI. 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 PI. 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 3,700 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 PI, including the yearly intensive course in PI offered in conjunction with the Clinical Immunology Society. The Repository, managed by Coriell, now contains cell lines from patients with a variety of PI; 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 of and participation in the Patient Registry, USIDNET staff attended patient and professional meetings in 2013. At the end of 2013, USIDNET was instrumental in helping secure funding through PCORI for PI CONNECT.

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. The IDF 2013 Advocacy Day on Capitol Hill was held in conjunction with the IDF 2013 National Conference. Inviting all National Conference attendees to join us on Capitol Hill in meetings with their elected officials, we saw almost 300 participants in this historic event. Our 2013 Advocacy Day was the largest gathering of patients with PI on Capitol Hill ever, with volunteers visiting 140 offices to meet with their members of Congress about issues important to the PI community. Eight separate Federal and State level calls to actions were sent through the IDF Action Alert system generating 3,239 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.

Jersey, New York, Ohio, Oregon, Pennsylvania, Rhode Island, Texas, Utah, Washington, West Virginia, Wisconsin and Wyoming. Also screening: District of Columbia and Navajo Nation. States currently planning to begin screening in 2014: Arkansas, Missouri, Nebraska, North Dakota, Oklahoma, Puerto Rico, South Carolina, Virginia. States where Advisory Committees have approved adding SCID, but have a longer timetable for implementation: Georgia, Maryland, and North Carolina.

In 2013, IDF translated into Spanish educational materials we developed for parents who learn their baby received an abnormal screen on the TREC test and for those who receive a positive diagnosis of SCID.

**Implementation of the Affordable Care Act**

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 and updating the IDF Health Insurance Toolkit to help patients find appropriate health insurance coverage. IDF also continues to monitor implementation on the state level advocating on issues relevant for patients with PI including opposition to state legislation that would allow automatic substitution of biosimilars without prior notification. IDF continues to educate patients about implementation efforts and opportunities for advocacy on the IDF website and at Patient Education Meetings and the IDF 2013 National Conference.

**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.

Of major concern to the PI community is the increasing trend of insurers shifting costs onto patients through the use of pharmacy benefit tiers. Some insurance plans place drugs into different tiered categories based on cost, placing expensive specialty medications like Ig into new specialty tiers. These specialty tiers are now commonly requiring patients to pay a percentage of the actual cost of these drugs – from 20% to 50% – often costing hundreds, even thousands, of dollars per month for a single medication. These practices are placing medically necessary treatments out of reach for average Americans. IDF joined the Coalition for Accessible Treatment (CAT) to advocate for a solution to this problem with introduction of the Patients’ Access to Treatments Act, HR 460. HR 460 was the main advocacy item for the IDF 2013 National Conference, and IDF continues to advocate for this important legislation through action alerts, petitions and work with Congressional offices. IDF also advocates at the state level, submitting testimony in support of legislation that caps out of pocket costs for medications covered under specialty tiers in six states: California, Delaware, Georgia, Maryland, Pennsylvania and Rhode Island. Legislation in Delaware was ultimately successful at capping specialty tier cost sharing at $150 per medication per month.

**Grassroots Advocacy**

Action Alerts have been very successful in mobilizing our community to raise awareness on critical issues. In 2013, IDF utilized the Action Alert system for three state level calls to action in response to SCID newborn screening legislation and specialty tier legislation. These were instrumental in campaigns that saw successful passage of legislation that created caps on specialty tier cost sharing and enactment of SCID legislation.

IDF filmed two new videos for the Advocacy Channel in 2013 – advocacy training for meetings with policymakers and SCID newborn screening in California. In 2013, video views of the Advocacy Channel totaled 3,285, the largest number of views in the channel’s history.

**Survey Research**

IDF national patient surveys provide crucial insight into the personal impact of PI 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 PI.

As such, in 1995, IDF undertook the first national survey of the state of PI in the U.S. The only national estimates of the characteristics and experiences of patients with PI are from the three National Patient Surveys conducted by IDF in 1996, 2002 and again in 2007.

In 2013, we conducted the 4th National Patient Treatment Survey. Over 1,600 individuals completed and returned their questionnaires. We were also finally able to schedule the second national survey of physicians and PI. The membership of the AAAAI was surveyed through the web first, and the remaining members were mailed a survey in August with returns still coming back at the writing of this report.

The IDF Survey Research Center continues to provide timely data, analysis and expertise on issues of importance to the PI community. During 2013, the Survey Research
Department has provided active assistance in the following areas:

- IDF 2012 National Patient Survey
- IDF 2013 National Treatment Survey & QOL Survey
  - Over 1,600 returned surveys
- Consulting for Primary Immune Deficiency Treatment Consortium
  - WAS, CGD
- Consulting for USIDNET
- IDF 2013 Physician Survey of PI
- Publication of “Indications of Autoimmunity and Auto-Inflammation in X-Linked Agammaglobulinemia” in the Journal of Allergy and Clinical Immunology
- Submission of manuscripts based on IDF survey data
  - Pediatricians
  - Family Practice
  - Women’s Reproductive Health Survey
  - Pulmonology

Communications

IDF communications manages the development and production of IDF resources, both print and online, providing vital information to patients, families and healthcare providers, continually expanding IDF’s e-presence, and engaging more members of the community. By expanding and engaging more people, IDF can connect more patients and family members seeking answers and looking for others who understand—ultimately this will help improve their quality of life.

In 2013 IDF communications continued to enlighten and inform our community with our newsletter, IDF ADVOCATE, published three times a year (circulation of 28,000), and a monthly e-newsletter, Primary Immune Tribune, (reaching over 200). Our new website boasted a 41% increase in visits over 2012. Our social networking sites, IDF Friends and IDF Common Ground, grew to almost 3,900 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 249,734 times. The IDF Arcade, filled with educational games for children of all ages, has been visited 1,336 times. IDF took advantage of external social media websites to promote programs and initiatives, and our numbers grew in 2013 with 5,179 facebook likes and 730 twitter followers. In September 2013, IDF created an Instagram account gaining 39 followers by the end of the year.

There were several new initiatives.

New Logo

After 33 years, a new IDF logo was created to present a fresh, updated presence on our online vehicles as well as all our printed materials. The community enthusiastically embraced it.

New Website

In 2013, to satisfy the demands of our growing community and to stay current with the latest web developments and mobile technologies, www.primaryimmune.org was redesigned and audited in 2013. The new design improves usability with a user-friendly navigation system, making information easier to find. On the home page, clear calls to action prioritize information, and a full width slider highlights events and programs. Most importantly, the site is now mobile responsive. More than 30% of users were accessing the site with smartphones and tablets, so it was redesigned to meet that need. All content on the site was audited, ensuring the most current information is available. New patient life stage sections were created, including sections for infants and children, teens, young adults, and adults. All chapters of the new handbook were added as individual web pages, expanding the amount of information easily accessible on the site.

IDF Reel Stories

Along with the overall website redesigned, the IDF Reel Stories page was revamped to make it easier for users to watch the more than 80 video testimonials detailing patient experiences living with PI. The new IDF Reel Stories page, or video hub, displays the videos as easy to view thumbnails and organizes the videos by the following categories:

- Patient Stories
- Parent Stories
- Type of Disorder
- Treatment Options
- Patient Lifestage
- Diagnosis Story
- Staying Positive
- Healthy Lifestyle
- Volunteer
- Patient Advocacy
In 2013, IDF published the new *IDF Patient & Family Handbook for Primary Immunodeficiency Diseases – 5th Edition*, a trusted resource for patients, families, and healthcare providers. This edition was developed by 44 contributors, including leading immunologists, healthcare providers, and life management experts. Editors were R. Michael Blaese, MD, IDF Medical Director; Francisco A. Bonilla, MD, PhD, Boston Children’s Hospital; Richard Stiehm, MD, University of California Los Angeles; and Elizabeth Younger, CPNP, PhD, Johns Hopkins.

Introduced at the IDF 2013 National Conference, this edition features new chapters and updated information about diagnosis, treatment, and life management. It expands the content of the Handbook by another 50% to 33 chapters with descriptions of nearly 100 different types of PI. The Handbook includes an overview of the immune system and PI to provide a basic description of the components of the immune system and how its defects lead to disease. There are 18 chapters covering the specific details of many types of individual types of PI themselves. There are additional chapters with general information relevant to the inheritance, laboratory diagnosis, general care and specific medical treatments as well as chapters on life management issues for patients of different ages. New chapters were added on subjects such as autoimmunity, allergies and infections-topics of critical interest to many in our community. There are also new chapters on stem cell and gene therapy, innate immune defects and an enlarged section on phagocytic cell disorders within the chronic granulomatous disease chapter.

**Clinical Focus on Primary Immunodeficiencies: Chronic Granulomatous Disease**

In 2013, IDF published *Clinical Focus Chronic Granulomatous Disease*, authored by Jennifer W. Leiding, MD University of South Florida, Department of Pediatrics, Division of Allergy, Immunology, and Rheumatology; Harry Malech, MD, Laboratories of Host Defenses, NIAID, NIH; and Steven M. Holland, MD, Laboratory of Clinical Infectious Diseases, NIAID, NIH. The publications, introduced at the IDF 2013 National Conference, outlines symptoms and diagnosis, as well as treatment and management of Chronic Granulomatous Disease (CGD).

**IDF Presents: Battle of the Bands - New Comic Book**

In 2013 the new IDF Comic Book was published. It complements IDF’s popular teen-friendly video *In Tune with Your Immune System*. This comic book version compares the human immune system to a rock band.

**National Primary Immunodeficiency Awareness Month and World PI Week**

In April 2013, IDF promoted National Primary Immunodeficiency Awareness Month and World PI Week (April 22-29). We provided the community with talking points on PI, FAQ’s, IDF Information Sheet. We encouraged patients and family members to host their own awareness and fundraising events, and we promoted Awareness Month and World PI Week through our all of our communications, including our newsletter, e-newsletter, website, IDF Friends, IDF Common Ground, facebook and twitter. During Awareness Month press release, IDF secured local media opportunities to promote PI awareness and the resources available from IDF.

**IDF Walk for Primary Immunodeficiency 2013**

In 2013, IDF launched the first Walk for Primary Immunodeficiency in Chicago, Los Angeles and Philadelphia. Overall, nearly 1,300 walkers participated, and more than $430,000 was raised from walkers and sponsors. IDF Walk for Primary Immunodeficiency supports vital IDF programs and services, and increases awareness about primary immunodeficiency across the country.

Walkers showed incredible enthusiasm at the Greater Philadelphia Walk, held Sunday, September 29 at Penn’s Landing. Teams of walkers arrived in customized team t-shirts—some even wore fun hats and socks. Walkers registered online prior to the event and received their own online fundraising page to create teams, add members and easily spread the word and raise funds. There were teams of coworkers, teams of classmates—patients and
families living with primary immunodeficiency really reached out and rallied those closest to them.

In Philadelphia, more than 500 walkers helped raise over $75,000. The Greater Philadelphia Walk committee, including Chuck Lage, Terry Halper, Judy Kozulak and April Sica, were dedicated to making the first walk go smoothly, and it definitely did!

On Saturday, October 19, IDF traveled to the West Coast for the Greater Los Angeles Walk at El Dorado East Regional Park in Long Beach. Like Philadelphia, the teams showed up in spirited gear with lots of energy. Special guest James Worthy, a former Los Angeles Laker and NBA Hall of Famer, attended to show his support and pump up the crowd. There were over 250 LA walkers and almost $65,000 was raised. Greater Los Angeles co-chairs Rich Low, and Kristy and Nick Cacucciolo did an amazing job!

IDF wrapped up in the Windy City for the Greater Chicago Walk on Sunday, October 27 at Cantigny Park in Wheaton, IL. The temperatures were a little cooler, but the crowds were just as motivated. There were more than 525 Chicago walkers, and over $90,000 was raised. There were many who made Greater Chicago walk a success including chair Amy Walsh, the Berryhill Family and the many members of the walk committee (too many to name).

In addition to the three national sites, Biotest hosted a local walk at their headquarters in Boca Raton, FL and many participated in the Nationwide Virtual Walk, which ran until December 31, 2013.
Leadership

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Terry Halper
Mary Hurley
Seth Kaufman
Chuck Lage
Robert LeBien
Richard Low, Jr.
Brian Rath
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; Seth Kaufman; and Brian Rath.

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Christine Belser
Vice President, Programs and Communications

Lawrence A. LaMotte
Vice President, Public Policy

Julie Nzambi
Human Resources & Office Manager

Sarah Rose
Director of Finance
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Loris Aro, RN
Sussman & Associates Immunology

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All Children’s Hospital

M. Elizabeth M. Younger CRNP, PhD – Chair
Johns Hopkins University School of Medicine
Each year leading companies in the healthcare industry provide financial support to 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 diseases (PI).

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 IDF patient meetings are offered throughout the country because of their generosity. 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, so funding from sponsors allows IDF to provide services and publications free of charge to our community.

Our sponsors understand the chronic nature of PI. Because the diseases never go away, patients and their families will continually rely on IDF, and we extend sincere appreciation to these companies for their continual support to make this possible.

**IDF Core Service Leaders**
- Baxter International Inc.
- CSL Behring
- Grifols

**IDF Core Service Supporters**
- Biotest Pharmaceuticals
- IgG America / ASD Healthcare / US Bioservices
- Octapharma

**IDF Sustaining Contributors**
- Kedrion Biopharma
- Vidara Therapeutics
- Walgreens – IG Therapy Program

**IDF Sponsors**
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- BioFusion
- BioRx
- BioScrip Specialty Pharmacy
- Coram Healthcare
- CVS Caremark
- Orsini Healthcare
- RMS Medical Products
## Consolidated Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2013

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td><strong>PUBLIC SUPPORT AND REVENUE:</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Public support:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions and grants</td>
<td>$4,234,335</td>
<td>$1,280,325</td>
<td>$7,000</td>
<td>$521,660</td>
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<tr>
<td>Net assets released from restrictions</td>
<td>1,445,410</td>
<td>(1,445,410)</td>
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<td>-0</td>
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<tr>
<td>Total public support</td>
<td>5,679,745</td>
<td>(165,085)</td>
<td>7,000</td>
<td>5,521,660</td>
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<tr>
<td>Government grants and other contract revenues</td>
<td>573,524</td>
<td>-0</td>
<td>-0</td>
<td>573,524</td>
</tr>
<tr>
<td><strong>Revenue:</strong></td>
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<tr>
<td>Investment income</td>
<td>204,782</td>
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<td>721</td>
<td>205,503</td>
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<tr>
<td>Other income</td>
<td>(780)</td>
<td>-0</td>
<td>-0</td>
<td>(780)</td>
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<tr>
<td>Special events</td>
<td>477,269</td>
<td>-0</td>
<td>-0</td>
<td>477,269</td>
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<tr>
<td>Total revenue</td>
<td>681,271</td>
<td>-0</td>
<td>721</td>
<td>681,992</td>
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<tr>
<td>Total public support and revenue</td>
<td>6,934,540</td>
<td>7,000</td>
<td>7,721</td>
<td>6,777,176</td>
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<tr>
<td><strong>EXPENSES:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program services:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical and scientific</td>
<td>1,091,753</td>
<td>-0</td>
<td>-0</td>
<td>1,091,753</td>
</tr>
<tr>
<td>Services to patients and families</td>
<td>4,112,536</td>
<td>-0</td>
<td>-0</td>
<td>4,112,536</td>
</tr>
<tr>
<td>Total expenses</td>
<td>5,204,289</td>
<td>-0</td>
<td>-0</td>
<td>5,204,289</td>
</tr>
<tr>
<td>Supporting services:</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Administration and finance</td>
<td>585,042</td>
<td>-0</td>
<td>-0</td>
<td>585,042</td>
</tr>
<tr>
<td>Marketing and fundraising</td>
<td>367,399</td>
<td>-0</td>
<td>-0</td>
<td>367,399</td>
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<tr>
<td>Total expenses</td>
<td>952,441</td>
<td>-0</td>
<td>-0</td>
<td>952,441</td>
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<tr>
<td><strong>CHANGE IN NET ASSETS</strong></td>
<td>777,810</td>
<td>(165,085)</td>
<td>7,721</td>
<td>620,446</td>
</tr>
<tr>
<td><strong>NET ASSET, BEGINNING OF YEAR</strong></td>
<td>5,252,503</td>
<td>1,695,390</td>
<td>33,691</td>
<td>6,981,584</td>
</tr>
<tr>
<td><strong>NET ASSET, END OF YEAR</strong></td>
<td>$6,030,313</td>
<td>$1,530,305</td>
<td>$41,412</td>
<td>$7,602,030</td>
</tr>
</tbody>
</table>
### Consolidated Statement of Functional Expenses

**For the Year Ended December 31, 2013**

<table>
<thead>
<tr>
<th></th>
<th>PROGRAM SERVICES</th>
<th>SUPPORTING SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medical</td>
<td>Services to</td>
</tr>
<tr>
<td></td>
<td>and Scientific</td>
<td>Patients and</td>
</tr>
<tr>
<td>Salaries</td>
<td>$321,267</td>
<td>$1,085,952</td>
</tr>
<tr>
<td>Employee benefits</td>
<td>35,745</td>
<td>117,801</td>
</tr>
<tr>
<td>Payroll taxes, etc.</td>
<td>28,908</td>
<td>92,446</td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>385,920</td>
<td>1,296,199</td>
</tr>
<tr>
<td>Professional fees</td>
<td>385,528</td>
<td>836,740</td>
</tr>
<tr>
<td>Training, conference, conventions, &amp; meetings</td>
<td>54,249</td>
<td>1,218,458</td>
</tr>
<tr>
<td>Travel</td>
<td>60,112</td>
<td>119,402</td>
</tr>
<tr>
<td>Awards and grants</td>
<td>44,449</td>
<td>41,700</td>
</tr>
<tr>
<td>Occupancy</td>
<td>22,956</td>
<td>106,667</td>
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<tr>
<td>Insurance</td>
<td>2,005</td>
<td>9,319</td>
</tr>
<tr>
<td>Printing and publications</td>
<td>53,807</td>
<td>189,967</td>
</tr>
<tr>
<td>Telephone</td>
<td>6,917</td>
<td>28,265</td>
</tr>
<tr>
<td>Postage and shipping</td>
<td>22,899</td>
<td>82,990</td>
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<tr>
<td>Supplies</td>
<td>13,144</td>
<td>18,697</td>
</tr>
<tr>
<td>Rental and maintenance of equipment</td>
<td>7,643</td>
<td>29,804</td>
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<tr>
<td>Miscellaneous</td>
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<td>20</td>
</tr>
<tr>
<td>Advertising</td>
<td>200</td>
<td>4,826</td>
</tr>
<tr>
<td>Dues and subscriptions</td>
<td>717</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>1,060,546</td>
<td>3,983,097</td>
</tr>
<tr>
<td>Depreciation and amortization</td>
<td>31,207</td>
<td>129,439</td>
</tr>
</tbody>
</table>

Total: $1,091,763 $4,112,536 $5,204,289 $585,042 $367,399 $952,441 $6,156,730
Donors

$500,000 and above
Baxter International, Inc.
CSL Behring
Grifols
National Institutes of Health

$100,000-$499,999
Biotest Pharmaceuticals Corporation
IgG America / ASD Healthcare / US Bioservices
Octapharma
Vidara Therapeutics, Inc.

$50,000-$99,999
Kedrion Biopharma
Teresa and Jeffery Puretz
Sigma-Tau Pharmaceuticals
Walgreens - IG Therapy Program

$25,000-$49,999
Accredo
American Legion Child Welfare Foundation
Axelacare
BioRx
BioScrip
Coram Specialty Infusion Services
Express Scripts

$10,000-$24,999
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The Hutsell Family Fund
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RMS
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Hershfield Family Charitable Fund
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Family Foundation
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Dawn and Robert Burns
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Surgical Associates
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Culver’s Frozen Custard
Butterburgers
June and James Curley
Katie Davidski
Dana De Vivo
Diamond Hills Auto Group
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Employees Charity Organization
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Mary and Ranjit Rath
Donna and Dennis Ready
Jennifer and Marc Richmond
Shelley and Jim Romeo
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Terry Schrock
Joan and Greg Schwarz
Alan Shaw
Tracy Shaw
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Medical Service
Laura and Jeff Uecker
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US Best
Irene and Lawrence Walsh
Jennifer Weyman-Chartoff and Robert Chartoff
Marilyn and Jerry Winkelstein, MD
Jay Wolfe
Julie and Peter Wyss

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American Express
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Lucy and Herbert Ballien
Molly and Mark Ballow, MD
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Shawna and Larry Bartlett
Victoria and B. Randolph Bateman
Danielle and Bryan Bauer
Christine and Chuck Belser
Aleece Bentzinger
Zina and Randy Berryhill
Lisa and James Betsworth
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Laune and Kenneth Brovold
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Tom Fitzgerald
Chris Fitzmaurice
Dayna and Brian Fladhammer
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Beatriz Gallegos
Ignacio Gonzalez
Barbara and Peter Goodman
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Carolyn Guin
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Gillian and David Hanus
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Mary and Lawrence Hennessey
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Carol Higgins
Larry Holstein
Gay and H. Bradley Howett
Ann and Gerry Huot
Mary and Alan Hurley
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IBPN Marketing Research Bureau, Inc.
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JSCS Limited Partnership
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Veronica and Brian Kaspkszak
Debra and Robert Kenney
Carol and Ray Kerstetter
Michael Kindzly
Ian Lapereire
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Sharol Holstein
James Lewandowski
Mary Litwiller
Krista Bock Mangan and
James Mangan
Maritz Dealer Solutions
Sherry Markham
Frances Massa
MassMutual Financial Group
Howard McCreesh
MD Logistics, Inc.
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Sandra and Aubrey Miles, Jr.
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Jill Moret
Gail and Sydney Nelson
Deborah and Peter O’Malley
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Council of Catholic Women
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Ruth and Rodney Parry
Amy Patterson
Sara and Jeremy Penn
Sue and Richard Petrelli
William Phillips
Pivot Design
Ellen and Robert Pratt
Nicholas Preddice
Linda and Elliott Puretz
Ellen Rabb
Norma Ramsey
$250-$499 (cont.)
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Trina and John Restivo
Rev3 Triathlon
Tara and Jeff Reynolds
Debra and Gregory Rich
G. Wendell Richmond
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Jacqueline Robinson
Rosa Maria’s
Daniel Ross
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Joseph Russo
Klaus Schaefer
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Randall Sexton
Anjmun Sharma
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Roberta Sickles
Simple IT Care
Amanda Skoskiewicz
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Marsha and Keith Smith
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Debra and Joe Stefanelli
Lisa and Kenneth Stevenson
Martin Suss
Nadina Szew
Pam and Bobby Taub
Carmen Thompson
Joanna and Christopher Tierno
Town of Chelmsford
True IA
United Refrigeration & Air Conditioning
United Stationers
Charitable Trust
Adrian Varas
Margaret Vaught
Victor Villarreal
Marilyn von KleinSmid-Randolph
Amy and Shawn Walsh
Cafe Press
Leonard Wislow
Andrea Witlin and Edward Dippolito
Cynthia and Joseph Zuraw

$100-$249
Anonymous (3)
A Quality Facility Services
John Adams
Kathleen Addison
Nell and Tom Addikson
Advanced Lith Printing & Bindery
Lydia and William Akerman
Marisol Alanis-Gonzalez
Norma and Dixon Aldridge
Sylvia Alexander
All County Exteriors
Heather and Larry Allen
Sharon and Ron Allen
Esther Allman
Annette and Carlos Almeida
Joann and Peter Almen
Molly and David Altbelli
Kathy and Steve Altbelli
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Terry Altschuler
Jack Alvino
David Amerson
John Amidei
Thomas Andersen
Chris Anderson
Jerald Anderson
Jonathan Anderson
Shannon Anderson
Susan Anderson
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Janina Arnwine
Carole and Estelle Art
James Art
Louie Aubert
Laurie and Michael Austin
Alicia and Charles Auzqui
Manny Ayala
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Colleen and Thomas Banks
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Susan and Brian Barnes
Linda and Brian Barrett
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Damon Bates
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Bentanu, LLC
Bentley Football Families
Karen Berger
Lindy Berggreen
Cynthia and Gregory Berlacher
Michael Bernhardt
Kelly Bertolazzi
Dorothy and Tristram Bethea
Bethlehem Baptist Church
Allen Bingen
Megan Birch
Linda Bishop and
Gilman Schultz III
Julie and Todd Black
Paul Black
Jerald Blutman
Angelique Bly
BNY Mellon
Christopher Bobbitt
Sheila and Krista Bock
Anne and Warren Boley
David Bond
Joanne Bonner
Jennifer Bono
Julia and Thomas Bontrager
Linda and Gary Bosko
Kathleen and Daniel Bosley
Samuel Botsford
James Boyle
V.P. Boyle
Janet Bradfield
Brainstorm Creative, Inc.
Michael Brauniger
Winnie and Craig Bratlien
Susan Brauns
Steve Brehmer
Kathleen and Roy Bremer
Alyssa Brennan
Linda Myers
Richard Brennan
Clarence Bringe
Bristol Myers Squibb
Emilee Brock
Patsy and Michael Broge
Steve Broll
Lynda Brotemarkle
Kathleen and Richard Brown
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Tong Zhang
Arlene Zilsko
Mary Zingales
Luanne and David Zipkin
Eunice Zordilla
Lucy Zurba
### IDF Walk for Primary Immunodeficiency Teams 2013

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<tr>
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<tr>
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IDF is grateful to the members of our community who raised funds on IDF’s behalf in 2013.

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 2013, the centers helped raise $155,213.44.

- Biotest Plasma
- CSL Plasma
- Grifols Plasma Center

The Immune Deficiency Foundation makes every effort to ensure the accuracy of donor and fundraiser 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.