

35 Years of Leading the Way
Immune Deficiency Foundation

2015 ANNUAL REPORT





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Mission Statement

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

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!

From Our Leadership

In 2015, the Immune Deficiency Foundation celebrated 35 years of leading the way for people living with primary immunodeficiency diseases. We have broadened our outreach, remained focused on innovation and strengthened our commitment to the primary immunodeficiency community.

We understand what's important — advancing diagnosis and treatment, quality healthcare and valuable education. Through the enduring work of dedicated volunteers, medical professionals, generous supporters and professional staff, our programs continue to produce untold numbers of benefits for thousands of individuals and families. We'll hope you'll take a moment to review the achievements of the Foundation over the past year detailed in this Annual Report.

We thank those who make the work of IDF possible. Because of so many, IDF's efforts keep growing stronger. Thousands depend on IDF for information, education and empowerment, and IDF will continue to lead the way for the primary immunodeficiency community for many years to come.

Sincerely,



Marcia Boyle

IDF President & Founder



John Seymour, PhD, LMFT

Chair, IDF Board of Trustees

Outreach



Because primary immunodeficiency diseases are rare, outreach to patients, families and healthcare professionals is critical. From presenting education meetings throughout the country, to creating programs specifically for teens and young adults to collaborating with healthcare professionals and raising awareness among the public, IDF works to sustain initiatives that build relationships within the community and provide them with the information and resources they richly deserve.

IDF 2015 National Conference

The primary immunodeficiency (PI) community gathered in New Orleans for the IDF 2015 National Conference, June 25-27, and the Crescent City served as the perfect setting for the high energy and enthusiasm of more than 1,360 attendees. The conference—the 8th in the Foundation’s 35-year history—gave individuals and family members the opportunity to learn from experts in the field and to meet with others who understand what it’s like to live with PI. A new mobile app helped attendees navigate the conference and all it had to offer.

The IDF National Conference is the only national meeting in the U.S. specifically for individuals and families living with PI, and for many attending it can be a transformational experience. As one conference participant commented, “Thank you for providing this opportunity for all of us to come together. It truly was life-changing for my family and myself.”

The three days included more than 40 presentations from world-renowned healthcare and life management experts covering various topics, including advancements in diagnosis and treatments for PI, allergies, antibiotic and antifungal therapies, autoimmunity, complementary and alternative medicine, nutrition, mental health, school, employment, health insurance and more. Attendees were invited to partake in all the fun of the IDF 2015 National Conference including a New Orleans style Welcome Reception, Breakfast Symposia, IDF Zebra Gala, IDF Night at Mardi Gras World and the introduction of TZ the IDF Zebra.

“Every presenter was more than willing to share time and information after presentations and throughout the conference,” said one attendee. “Very professional, polite, and knowledgeable on their area of expertise.”

IDF 2015 NATIONAL CONFERENCE STATS:



1,366 Attendees – *largest ever!*

66 Speakers

182 in the Youth Program

98.6% Would Recommend the IDF Conference



39 States

12 Countries



| | |
|-----------|----------------------|
| Australia | Italy |
| Belgium | Slovenia |
| Canada | South Korea |
| England | Switzerland |
| Germany | United Arab Emirates |
| Israel | United States |

IDF Education Meetings



Patient education is central to our mission, and each year IDF holds patient education meetings throughout the country. IDF has made a commitment to further enhance and increase the number of local patient education meetings throughout the U.S. Efforts have been made to partner with physicians nationwide to reach more patients and enrich the content of the meetings.

In 2015, IDF hosted 27 Patient Education Meetings and Family Conference Days, which are daylong meetings where local experts present medical and life management sessions to adults. Family Conference Days include a youth program for ages 5 and up. Through these meetings, IDF reached 1,634 individuals. We had over 121 speakers volunteer to present at the meetings.

IDF Get Connected Groups

IDF Get Connected Groups are designed to connect individuals and family members living with PI in their local communities. The meetings can occur at a local community room, library, coffee shop, church or other venue. They provide an opportunity for individuals to network and receive support in their local community. In 2015, 48 Get Connected Groups, hosted by IDF volunteers, were held in 11 cities in 10 states. Through these meetings, IDF reached a total of 304 individuals.

IDF Volunteer Network

The IDF Volunteer Network is committed to supporting the mission of IDF. This nationwide network of dedicated volunteers has been recently restructured so that volunteers can advance the reach of IDF in areas of strategic importance to the PI community. In 2015, 169 individuals requested peer support. Since some individuals were networked with more than one volunteer, volunteers were contacted approximately 250 times to provide support. IDF staff has interacted with 562 individuals interested in volunteering or managing volunteer activities. In 2015, the volunteer program was enhanced with new recruitment methods, online and print training materials, and expanded volunteer opportunities to better serve the PI community. Some of these opportunities include: IDF Get Connected Leaders, IDF Liaisons, Office Support, Peer Support Coaches, Plasma Center Visitors, Walk Advisors, Walk for PI – Event Day Volunteers and Walk Planning Team Members.

IDF Outreach Initiative

Launched in 2015, the IDF Outreach Initiative expands the reach and impact of IDF nationwide. Through the initiative, volunteers serve as IDF Liaisons or IDF Get Connected Leaders to help us reach those in the PI community. IDF Liaisons connect and build relationships with healthcare professionals who care for individuals diagnosed with PI, as well as with clinicians who are likely to see these patients. IDF Get Connected Leaders increase connections between patients in their communities.

These are exceptional opportunities for motivated individuals who want to make a difference for others living with PI. They understand the importance of education, understanding and encouragement in helping individuals live a fulfilling life with PI.

IDF Teen Program

The IDF Teen Program, specifically for teens with PI, provides education and support while fostering leadership and advocacy skills for teens. The program encourages teens to live life to the fullest and creates opportunities for parents of teens in the PI community to meet one another, learn about PI and discover ways to support their teen.

Teens have a chance to meet face-to-face at IDF Teen Escape weekends, which 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. Teens enjoy a night of fun and comradery at local Dave and Busters playing games and enjoying the company of others within the PI community. In 2015, IDF Teen Escape weekends were held in Baltimore, MD and Kansas City, MO with a total of 177 individuals attending.

Training is offered to teen volunteers on the IDF Teen Council, and council members provide support at various IDF programs and interact with other teens on IDF Common Ground. The IDF website offers an entire section devoted to Teens that is filled with advising about living with PI as a teen, which can be found at www.primaryimmune.org/teens/. IDF provides multiple opportunities for teens to develop into strong, capable individuals.

IDF Teen Program

- IDF Teen Escapes – Weekend getaways for teens with PI
- IDF Teen Council – Leadership opportunities for teens with PI
- Web-based IDF Teen Program
 - Teen Life Stage Section of IDF website
 - IDF Common Ground, the social network exclusively created for teens living with PI where they can connect, share ideas and support one another.
- Information to help parents/caregivers of teens with PI

“It helped me become more social with people that can relate to me and helped me understand the disease that I have...”

– Casey, IDF Teen Council Member

IDF Young Adult Program

The IDF Young Adult Program was developed specifically for young adults to meet the needs and interests of this group. The program tackles the unique issues faced by young adults with PI (ages 18-30) all while connecting young adults within the community. In 2015, IDF offered the first young adult networking opportunity and session at the IDF 2015 National Conference. From those discussions, planning began for the new IDF Presents: PI Voices, IDF Young Adult Webinar Series in 2016, in which participants can ask questions and discuss concerns with a live panel who share similar experiences of living with PI.

IDF Medical Programs

IDF actively promotes and develops medical education and resources to improve the diagnosis, treatment and care of PI. IDF continues to strengthen its outreach to healthcare professionals.

We strive to increase visibility in the medical community by attending national medical conferences that generally include an exhibit in the exhibition hall. Staff may interact with healthcare providers who see patients with PI to discuss educational opportunities, distribute educational literature and discuss IDF resources. IDF typically exhibits at five medical conferences each year, including but not limited to the American Academy of Allergy, Asthma and Immunology; American Academy of Pediatrics; Clinical Immunology Society; Immunoglobulin National Society; Infusion Nurses Society; American Academy of Family Physicians; National Conference for Nurse Practitioners; and the American College of Allergy, Asthma & Immunology.

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. In 2015, 94 physicians took advantage of this service, and as of May 2016 79 physicians have used this 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 resident's conferences. This program is available at no cost to the participating hospital. In 2015-2016, visiting professorships were held in eight locations, including Children's Hospital of Pittsburgh, Advocate Christ Medical Center, Kapiolani Medical Center, Wake Forest School of Medicine, University of California San Diego, Walter Reed Medical Center, Medical College of Wisconsin and Penn State Hershey Medical Center. We reached approximately 1,300 attendees.

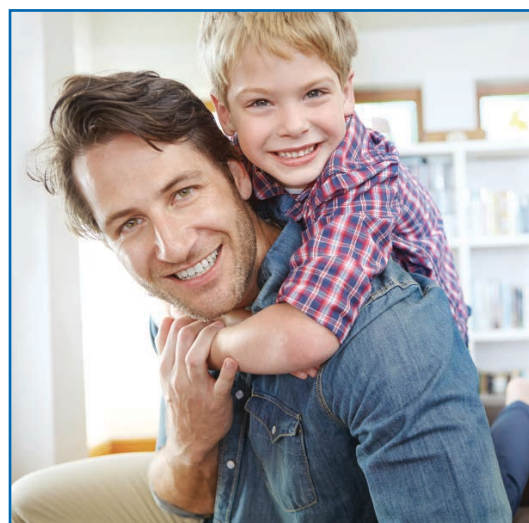
National Primary Immunodeficiency Awareness Month (April) and World PI Week (April 22-29)

IDF promoted National Primary Immunodeficiency Awareness Month in the U.S. in conjunction with World PI Week (WPIW), April 22-29. IDF is an active member of the WPIW Steering Committee, working closely with partner organizations to develop and execute the worldwide campaign.

IDF created an awareness poster promoting the resources available for those living with PI from IDF, and volunteers distributed the posters to their healthcare providers. *A Zebra Tale from the Immune Deficiency Foundation*, an illustrated storybook for children of all ages, was published during Awareness Month, and individuals and families were encouraged to order the book as well as all other IDF publications and awareness materials. IDF conducted an active social media campaign throughout April, asking followers to share facts and submit their own photos and experiences, using campaign hashtags #piawareness #thinkzebra. Many IDF meetings and events were held during the month of April, including the first IDF PI CONNECT Research Forum Webinar (see page 7) and IDF Advocacy Day 2015 (see page 15).

LivingwithCGD.org – The IDF Resource for Chronic Granulomatous Disease

Because it is so rare, IDF developed a website dedicated to the Chronic Granulomatous Disease (CGD) community, LivingwithCGD.org. Launched in January 2015, the site boasts comprehensive medical and life management information from CGD experts as well as additional resources for patients and families. The site features videos from individuals living with CGD, and the integrated blog features news, events and patient stories. The videos and blog posts are designed to engage more patients and reach out to existing CGD networks and groups on social media. The site and the regular blog posts are powerful tools IDF uses to directly reach the CGD community in an authentic and meaningful way.



Innovation



Over the years, IDF has worked to help advance research of primary immunodeficiency diseases. True innovation lies within the experiences of our patients and the data they can provide to better understand these rare disorders. Working collaboratively with expert clinicians from across the country, IDF's major focus is to better understand patient experiences and improve outcomes. In that regard, IDF conducts surveys of patients and physicians to gain a more complete representation of patient attitudes and experiences. In recent years, we have leveraged technology to help give researchers insight into the patient experience as well as give patients tools to better track their health. IDF continues to be nationally recognized for our critical work and valuable resources.



White House Champion of Change for Precision Medicine

On July 8, 2015, Marcia Boyle, IDF President & Founder, was one of nine individuals recognized by the White House as “Champions of Change” for Precision Medicine, which honors the work being done by patients, researchers, innovators and advocates who are advancing our understanding of health and disease by harnessing data to account for individual differences in people’s genes, environments and lifestyles to improve patients’ health.

The President’s Precision Medicine Initiative was launched in early 2015 to enable a new era of medicine through research and technology that empowers patients, researchers and providers to work together toward development of individualized treatments. Marcia was chosen as a Champion of Change for her work at IDF, specifically IDF ePHR and IDF PI CONNECT.

IDF PI CONNECT and IDF ePHR

In 2014, IDF developed a revolutionary research network focused on Primary Immunodeficiency (PI)—IDF PI CONNECT, the IDF Patient-Powered Research Network. IDF PI CONNECT empowers patients to participate and help transform research by consenting to share their data and their individual experiences. This is truly part of a national movement of Precision Medicine that will help researchers find answers, ultimately individualizing treatment and providing better outcomes for patients. IDF received a grant from the Patient-Centered Outcomes Research Institute (PCORI) to develop IDF PI CONNECT, which brings together patient-entered data from IDF ePHR, the online personal health record for people with PI, with clinical data from the United States Immunodeficiency Network (USIDNET), the only national patient-consented registry for PI in the U.S. And to truly bring patients into the research conversation, patients can let their voices be heard in the IDF PI CONNECT Research Forum. As part of the Forum, users can participate in exclusive live webinars covering a variety of topics relevant to the PI community. Bringing together this information and the patient voice holds great promise to provide researchers further insights about the diagnosis and treatment of PI, ultimately helping to improve quality of life for patients.

Individuals become a part of IDF PI CONNECT through IDF ePHR, our electronic personal health record, providing our users with the latest advancements in health record system management. The state-of-the-art platform, now used by over 2,100 individuals, enables users to enter and access their data no matter where they are with helpful, user-friendly features, transforming how individuals and caregivers manage health information. Two exciting new features in 2015 included an IDF ePHR mobile app that makes it even easier for users to track their health information from mobile devices, and a custom Health Calendar that allows users to track changes to their health in real-time. These features, along with the ability to upload many different types of electronic medical information into IDF ePHR, IDF helps patients get the most out of their healthcare visits.

Individuals who wish to contribute to research can easily consent into PI CONNECT through their IDF ePHR account. This allows patients with PI to donate the information they enter into their IDF ePHR to the USIDNET Registry for use in clinical research.

IDF PI CONNECT Research Forum

IDF PI CONNECT currently has more than 1,400 individuals consented to share their information, and many of these individuals are taking part in Research Forum discussions, where they can find the latest research and pose questions they have. The Forum brings together patients and healthcare professionals to drive more individualized and patient-centered research on the treatment and management of PI, such as which antibiotic works best to prevent bronchitis, how different dosing strategies compare, or what laboratory studies can predict autoimmune diseases. The Forum enables patients and scientists to collaborate and shape the direction of research to ensure that all patients benefit from the best treatment information available.

Live Research Forum webinars are an integral component of IDF PI CONNECT. Our first webinar, Less Common Aspects of Common Variable Immune Deficiency (CVID), held April 23, 2015, was a tremendous success with more than 150 participating. With such momentum from the webinar and activity in the Forum, IDF wanted to bring these discussions to the



IDF 2015 National Conference. We held a IDF PI CONNECT Live! Research Forum during the conference, moderated by IDF PI CONNECT Principal Investigator Kathleen Sullivan, MD, PhD of Children's Hospital of Philadelphia and Vice Chair of the IDF Medical Advisory Committee. Dr. Sullivan explained how the landscape of research is changing and the PI community can be an active participant in research. During this live forum with 75 attendees, researchers led dynamic discussions on four topics taken directly from Forum threads, including Transplant Research, Fever and Body Temperature, Ig Therapy: Choosing the Right One, Alternative Administrations, and Prophylactic Antibiotics. IDF also conducted interviews with researchers at the National Conference that were posted in the Forum.

The next Forum webinar topic was taken directly from the Live! Research Forum: Body Temperature and Fever Response. This topic is particularly important as many patients have expressed concerns over starting with a lower body temperature than normal (98.6 degrees), meaning a slight fever could be overlooked by a medical provider. This webinar, held October 29, 2015, explained these occurrences and provided attendees with valuable knowledge they can use to improve their visits with medical providers.

Patient discussions in the Forum and during the webinars are demonstrably driving research. Plans for an IDF research study examining body temperature and fever response are already underway.

Through IDF PI CONNECT, robust data direct from patients along with meaningful discussions with them will help researchers better understand the patient experience, leading to improved patient care.

The initial grant from PCORI enabled IDF to develop the IDF PI CONNECT platform. In 2015, IDF was awarded an additional three year PCORI award to continue the project and transform the infrastructure built in the first year to ensure patient-centered research.

PROMIS-29 Quality of Life Survey through IDF ePHR

Quality of Life (QoL) surveys assess an individual's ability to perform routine physical and social activities, and they compare the individual's score to the average scores of the larger U.S. population. This can provide useful comparisons to measure your health against others. The information from QoL surveys, known as Patient Reported Outcomes (PRO's), come directly from the patients' responses without any interpretation by a healthcare provider, or anyone else.

Starting in 2015, IDF ePHR hosts the PROMIS-29 surveys every six months. PROMIS, which stands for Patient-Reported Outcomes Measurement Information System, was developed to support NIH-funded research. PROMIS measures are standardized to assess patient-reported outcomes, such as pain, fatigue, emotional distress, physical functioning and social role participation, based on common metrics allowing for comparisons among chronic conditions as well as the general population. Using short questionnaires, the PROMIS-29 assesses seven health categories: Physical Function, Pain, Interference, Fatigue, Depression, Anxiety, Sleep Disturbance, and Ability to Participate in Social Roles.

IDF provides survey participants with instant customized reports of how their health compares to the general population. This information can be used as a way to better manage one's health and help healthcare providers better guide one's care. Additionally, patients who participate in PI CONNECT can share their PROMIS-29 PRO's with the USIDNET Registry, allowing the patient voice to enrich clinical research.

United States Immunodeficiency Network (USIDNET)

The United States Immunodeficiency Network (USIDNET) was established to advance scientific research in PI and provide resources for work on PI, including the establishment and expansion of a patient registry, a program for the education and mentoring of young investigators, and the maintenance of a cell repository for use in research.

In 2015, IDF PI CONNECT data was successfully integrated into the USIDNET registry and enrollment increased to 5,628, plus 29 new researcher queries.

The cornerstone of this initiative is a registry of patient information, and the strength of this registry lies with individuals with PI. More than 5,000 patients with PI have enrolled in the USIDNET Registry. Every patient's participation is critical to expand enrollment so an understanding of each disease is possible. Living with PI makes life experiences unique. However, when those experiences and those of other patients are examined collectively, common findings can help develop vital research and improve the quality of life for the entire PI community. USIDNET, a program of IDF, is funded by the National Institute of Allergy and Infectious Diseases (NIAID) a part of the National Institutes of Health (NIH), an agency of the Department of Health & Human Services.

Additionally, USIDNET collaborated with the Clinical Immunology Society (CIS) and The Jeffrey Modell Foundation (JMF) for the implementation of the Following Infants with Low Lymphocytes (FILL) project, which allows the collection of important and specific medical information about the first year of life for infants who are identified at birth, or shortly after, as potentially having a PI.

Funding for the use of registry data for publications was renewed in 2015, and the following publications were created using this data:

- Tuano KS, et al. Food allergy in patients with primary immune deficiency diseases: prevalence in USIDNET. *J Allergy Clin Immunol.* 2015: 135, 273–275.
- Al-Herz W, et al; Combined immunodeficiency in the United States and Kuwait: Comparison of patients' characteristics and molecular diagnosis. *J Clin Immunol.* 2015: 161:170-3.
- Leven E, Maffucci P, Ochs H, Scholl P, Buckley R, Fuleihan R, Geha R, Cunningham C, Bonilla F, Conley ME, Ferdman R, Hernandez-Trujillo V, Puck J, Sullivan K, Secord E, Ramesh M, Cunningham-Rundles, C. Hyper IgM Syndrome: a Report from the USIDNET Registry. *J Clin Immunol.* 2016; 36(5):490-501.

IDF Survey Research

IDF national patient surveys provide crucial insight into the personal impact of PI and help the Foundation develop initiatives 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.

The IDF Survey Research Center continues to provide timely data, analysis and expertise on issues of importance to the PI community.

IDF SURVEY RESEARCH MAJOR PROJECTS & ACCOMPLISHMENTS 2015

- IDF 2015 National Health Insurance Survey – Over 1,600 returned surveys.
- Immunologist Perspectives on Assessment and Management of Lung Disease in COVID: A Survey of the Membership of the Clinical Immunology Society and the European Society for Immunodeficiencies.
 - Over 300 Immunologists from CIS & ESID participated.
 - Creating two manuscripts for publication with Dr. Javeed Akhter.
- Consulting for Primary Immune Deficiency Treatment Consortium on the Wiskott-Aldrich Quality of Life Survey and non-medical needs survey.
- Consulting for USIDNET on the CGD Survey.
- Publications:
 - Hernandez-Trujillo, V. P., Scalchunes, C., Hernandez-Trujillo, H. S., Boyle, J., Williams, P., Boyle, M., & Orange, J. S. (2015). Primary Immunodeficiency Diseases: An Opportunity in Pediatrics for Improving Patient Outcomes. *Clinical Pediatrics*, 54(13), 1265-1275.
 - Gundlapalli, A. V., Scalchunes, C., Boyle, M., & Hill, H. R. (2015). Fertility, Pregnancies and Outcomes Reported by Females with Common Variable Immune Deficiency and Hypogammaglobulinemia: Results from an Internet-Based Survey. *Journal of Clinical Immunology*, 35(2), 125-134.
 - Orange, J. S., Seeborg, F. O., Boyle, M., Scalchunes, C., & Hernandez-Trujillo, V. (2016). Family Physician Perspectives on Primary Immunodeficiency Diseases. *Front. Med. Frontiers in Medicine*, 3.
- IDF manuscript based on survey of pulmonologists has been submitted.

IDF Survey Research consults for the Primary Immune Deficiency Treatment Consortium (PIDTC) and the United States Immunodeficiency Network (USIDNET), and supports IDF ePHR and IDF PI CONNECT.

IDF Medical Advisory Committee and IDF Nurse Advisory Committee

IDF is fortunate to have a Medical Advisory Committee (MAC) and Nurse Advisory Committee (NAC) comprised of prominent immunologists and clinicians dedicated to support the mission of IDF through the development of science-based standards and resources.

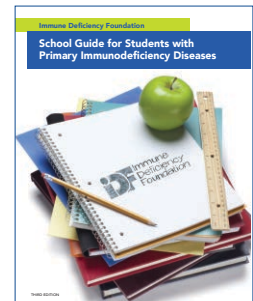
In 2015, members of the MAC published a resolution, “Immune Deficiency Foundation Medical Advisory Committee Resolution: The danger posed by the arbitrary insurer requirement for a diagnostic vaccine challenge for all previously diagnosed individuals with Common Variable Immunodeficiency (CVID).”

IDF Publications

Heralded as the best patient resources for PI in the world, IDF publications are developed by world renowned immunologists and healthcare professionals. In 2015, there were five new publications introduced.

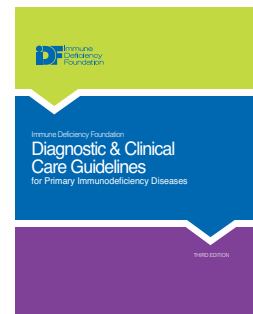
Immune Deficiency Foundation School Guide for Students with Primary Immunodeficiency Diseases, Third Edition

Printed in 2015, the *IDF School Guide for Students with Primary Immunodeficiency Diseases* is a valuable reference for parents and school personnel. It contains key medical points about PI diseases and associated special needs legal rights, and resource referrals. This edition includes new information regarding federal laws and health insurance, and it incorporates helpful information about transitioning from high school to post-secondary education. More sample letters and forms were added.



Immune Deficiency Foundation Diagnostic & Clinical Care Guidelines for Primary Immunodeficiency Diseases, Third Edition

Immune Deficiency Foundation Diagnostic & Clinical Care Guidelines for Primary Immunodeficiency Diseases was completely updated in 2014, and it was then printed and promoted in 2015. These guidelines were developed by expert immunologists to enhance earlier diagnosis, improve health outcomes and increase access to specialized healthcare and treatment. In addition to a new section on Mendelian Susceptibility to Mycobacterial Disease and updated International Classification of Diseases (ICD) codes, the existing sections have all been updated with the latest recommendations and treatment information for PI.



A Zebra Tale from the Immune Deficiency Foundation

In 2015, IDF proudly published the long-awaited *A Zebra Tale from the Immune Deficiency Foundation*, an illustrated storybook written for children—young and old—living with PI and their families to provide hope and encouragement. *A Zebra Tale* chronicles the journey of a young horse who faces recurrent infections, struggles to understand why he gets sick often, and ultimately finds contentment and acceptance when he is diagnosed with a PI, discovering that he is a zebra. The publication was made possible by the American Legion Child Welfare Foundation. Healthcare professionals, educators, adults and children in the IDF community gave their helpful feedback throughout the creation of the story.



IDF Publications continued

Clinical Focus on Primary Immunodeficiencies: Subcutaneous Immunoglobulin Replacement

In June 2015, IDF published *Clinical Focus on Primary Immunodeficiencies: Subcutaneous Immunoglobulin Replacement*. This publication, released at the IDF 2015 National Conference, was authored by Francisco A. Bonilla, MD, PhD, Director, Clinical Immunology Program, Boston Children’s Hospital, and Associate Professor of Pediatrics, Harvard Medical School; and Carla Duff, CPNP, MSN, CCRP, Advanced Registered Nurse Practitioner, University of South Florida.

It was edited by Mark Ballou, MD, Director, Allergy and Immunology Training Program, University of South Florida/All Children’s Hospital. It was approved by the IDF Medical Advisory Committee.



Immune Deficiency Foundation Clinical Focus on Primary Immunodeficiencies: Diagnostic Approaches to Antibody Deficiencies

In October 2015, IDF published *Immune Deficiency Foundation Clinical Focus on Primary Immunodeficiencies: Diagnostic Approaches to Antibody Deficiencies*. This publication was authored by Kathleen E. Sullivan, MD, PhD, Children’s Hospital of Philadelphia, Chief, Division of Allergy and Immunology; University of Pennsylvania, Perelman School of Medicine, Professor of Pediatrics. It was edited by Terry Harville, MD, PhD, Arkansas Children’s Hospital, University of Arkansas for Medical Sciences, Departments of Pathology and Laboratory Services and Pediatrics; and Jordan Orange, MD, PhD, Texas Children’s Hospital, Chief, Immunology, Allergy and Rheumatology, Baylor College of Medicine, Department of Pediatrics; Professor of Pediatrics, Pathology and Immunology, Vice Chair for Research. It was approved by the IDF Medical Advisory Committee.



Commitment



IDF understands the chronic nature of primary immunodeficiency diseases. Knowing first-hand how members of the PI community face significant challenges, it is a priority of the Foundation to identify and develop resources and services to meet the needs of those who live with PI – whether a patient is newly diagnosed or has been living with PI for years. Because the diseases never go away, individuals and their families will continually rely on IDF. With that in mind, we have made a commitment to the PI community and developed programs to ensure a better future for generations to come.

Nationally Recognized

IDF proudly works with organizations to better serve the Primary Immunodeficiency (PI) community. IDF is a member of the National Health Council, which is made up of more than 100 national health-related organizations and businesses, including the nation's leading patient advocacy organizations. IDF meets the National Health Council Standards of Excellence Certification Program®, a set of good operating practices to ensure that its patient advocacy group members maintain the highest standards of organizational effectiveness and public stewardship. For the third consecutive year, IDF has been awarded a 4-Star Rating from Charity Navigator, America's largest independent charity evaluator. This top distinction is awarded for sound fiscal management practices and commitment to accountability and transparency.

Patient Advocacy

IDF assists individuals with PI with a broad array of services including inquiries related to diagnosis, treatment, health insurance, peer support and literature requests. In 2015, IDF's patient advocacy services helped fill the need for over 7,021 requests from individuals and families seeking education, information and assistance, which is 560 more than 2014. IDF has answers and information when patients and families need it—online or by phone. That is the power and the dependability of IDF.



The top three reasons that patients contact IDF are for:

1. Education
2. Assistance in locating an immunologist in their area
3. Assistance in dealing with health insurance problems

Navigating Health Insurance

The majority of patients with PI rely on some form of insurance to assist with expenses, but dealing with health insurance and understanding the maze of issues involved can be overwhelming. An IDF staff member offers individualized assistance when a patient or caregiver contacts the Foundation in regards to insurance problems. Issues range from co-pay and premium assistance to insurance denials for treatment. In 2015, there were more than 300 calls regarding insurance. In 2015, IDF staff also worked with patients, providers and insurers to advocate for an appropriate updated medical policy for intravenous immunoglobulin (IVIG).

To offer additional resources, the IDF website features the IDF Patient Insurance Center, providing patients with regularly updated information and resources when it comes to health insurance, including information regarding the Affordable Care Act (ACA), state health insurance marketplace plans, manufacturer and assistance programs, how to appeal an insurance denial, frequently asked questions and more. To help individuals make the best possible choice in selecting a private health insurance plan, users can also download the IDF Health Insurance Toolkit which includes comprehensive information and resources along with helpful worksheets and a glossary of terms.

Peer Support

The IDF Peer Support Program is a caring community that connects people and patients who share similar relationships to PI. Feelings of isolation often accompany the everyday effects of living with PI. Frequently, those feelings stem from the perception that no one understands what you are going through. Sometimes a patient or family member simply needs to talk freely about how their feelings. Participation in the Peer Support Program gives patients and/or family members the opportunity to interact with one of IDF's peer support volunteers, who is a trained volunteer with personal experience living with PI. In 2015, 169 individuals requested peer support.

Custom Social Networks Specifically for PI Community: IDF Friends and IDF Common Ground

IDF Friends is a social network designed for patients and family members living with PI. Because the site requires login and the information is closed to search engines, IDF Friends users see the site as a safe, private, and comfortable alternative to Facebook, and a place where they can discuss issues and concerns that they might not discuss elsewhere. There is a wealth of user-generated information on the IDF Friends site, and it continues to be one of the first places people turn for advice. It continues to attract an average of 85 new users each month, and in total, the 5,108 members on the site have posted over 36,400 times on 4,280 topics.

IDF Common Ground, a social networking site exclusively for teens living with PI, creates a welcoming community for teens to connect, share ideas and support one another. It is a way for teens to communicate with others who are affected by PI, regardless of geographic location, and they can use the discussion forum to talk about health-related questions and individual concerns. An IDF staff member welcomes new registrants and generates discussion forum topics and features to stimulate user interest. In 2016, IDF developed a Common Ground app, which was requested by the teens and is the preferred way for teens to access a social network.

IDF Walk for Primary Immunodeficiency

IDF Walk for Primary Immunodeficiency helps create a better future for those living with PI, who face an increased vulnerability to infections, endure recurrent health problems and often develop serious illnesses throughout their entire lives. They deserve better.

Held across the country, the walks support vital IDF programs and services, power research to help the next generation and increase awareness to advance early diagnosis and proper treatment. The walks bring together a passionate community and have raised over \$2 million since the first walk in 2013.

In 2015, over 3,500 walkers and 378 teams participated at one of nine sites in the U.S. Locations included Boston, Cleveland, Greater Chicago, Fort Lauderdale, Houston, Los Angeles, Minneapolis, New York City and Philadelphia. For those who didn't live near one of our sites, they were able to use our virtual walk program.

In 2015, a gross revenue of \$1,016,676 was generated from IDF Walk for PI, representing a year to date increase of 42%.



In 2015, we introduced IDF Community Walks, created by members of the PI community who want to have a walk in an area that does not yet have an existing IDF-organized walk. Coordinated by dedicated volunteers in the PI community, these walks help fill in the geographical gaps between the IDF-organized walks. Charlotte and Omaha were our inaugural sites.

We continued success with IDF Order of the Zebra, our leadership fundraising club. The order is the elite group of fundraisers whose efforts make an extraordinary impact on the success of the walks. If walkers set a fundraising goal of \$1,000 or more on their personal fundraising page, and then reach that goal, they are inducted into the IDF Order of the Zebra. Overall in 2015, IDF had 83 members raise over \$1,000 and become a part of the club.

There were over 51,449 unique sessions on www.walkforPI.org, and the IDF Walk for Primary Immunodeficiency Facebook page gained an additional 685 followers to bring our total to 1,963 fans. Engaged constituents also promoted the walk through Facebook events for each walk across the country.

Public Policy

Through advocacy efforts, IDF lays the groundwork for the promise of an easier tomorrow. By mobilizing individuals, families and healthcare providers throughout the country, IDF stays at the forefront of issues relevant to this community. Public policy issues that are critical to patients at national and state levels are monitored through the IDF Advocacy Center, and our Grassroots Advocacy Program organizes individuals to contact their government representatives to promote healthcare legislation that will positively affect the community.

We believe that healthcare professionals, in consultation with their patients, should make decisions about care and changes in treatment. Clinicians are in the best position to understand the specific medical history and unique needs of each patient. Whether created by private insurers or public payers such as Medicare and Medicaid, IDF advocates for:

- Reduced out-of-pocket costs.
- Eliminating co-insurance on specialty tiers.
- Expanded specialists in-network, avoiding narrow networks.
- Access to the appropriate treatment at the appropriate site of care for each patient.
- Improvement of payer immunoglobulin medical policies.

IDF Advocacy Day 2015

On April 30, 2015, the Immune Deficiency Foundation (IDF) held its annual Advocacy Day in Washington, DC. Over 60 members of the primary immunodeficiency (PI) community (pictured above) made their way to Capitol Hill to advocate on behalf of those with PI and in support of The Patients' Access to Treatment Act (PATA), HR 1600, which seeks to restrain out-of-pocket costs for patients who use expensive specialty drugs, such as immunoglobulin (Ig) therapy—a life-saving treatment for many patients with PI.

HR 1600 is bipartisan legislation that will help ensure patients with chronic, disabling and life threatening conditions access to the treatments they need. It would limit out-of-pocket costs for medications in a specialty drug tier (typically Tier IV or higher) to the dollar amount applicable to the drugs in a non-preferred brand drug tier.

Dedicated IDF advocates, from teens to retirees representing more than 30 different states, attended over 135 meetings to garner support for HR 1600. They put a face to PI and emphasized why the passage of HR 1600 is so critical to the PI community. The results of their hard work were evident soon after, as several legislators made commitments to co-sponsor HR 1600.

Medicare IVIG Access Demonstration Project

The goal of the Medicare IVIG Demonstration Project is to prove the cost effectiveness of allowing Medicare patients with PI access to home infusions of IVIG. The demonstration began enrollment in August 2014 with the first home infusions covered beginning October 1, 2014. IDF works collaboratively with Centers for Medicare and Medical Services to help monitor and promote the project. Nearly 1,100 beneficiaries enrolled in 2015.

IDF Cadillac Tax

As part of the Patient Protection and Affordable Care Act (PPACA, as amended by the Health Care and Education Reconciliation Act of 2010), an annual 40% excise tax on "high-priced" employer-sponsored health insurance plans with annual premiums exceeding \$10,200 for individuals or \$27,500 for families will begin in 2018. In 2015, Congress voted overwhelmingly to delay implementation of the Cadillac Tax on high-cost health plans until 2020, a rare display of bipartisan agreement.

Biosimilars

IDF advocates that patients have access to safe and effective biologic and biosimilar medicines. Biologic medicines are made from living organisms and are far more complex than traditional chemical drugs. IDF is a member of the Patients for Biologics Safety & Access (PBSA), a national coalition representing 24 patient advocacy organizations working to ensure that the voices and interests of patients are heard as the FDA considers approval of a new category of drugs known as biosimilars. In 2015, along with PBSA, IDF participated in the Senate Hearing regarding biosimilars.

SCID Newborn Screening

IDF continues to be the grassroots leader in working to have newborn screening for Severe Combined Immune Deficiency (SCID) in all 50 states. Babies with SCID appear healthy at birth, but without early treatment, most often by bone marrow transplant from a healthy donor, these infants cannot survive.

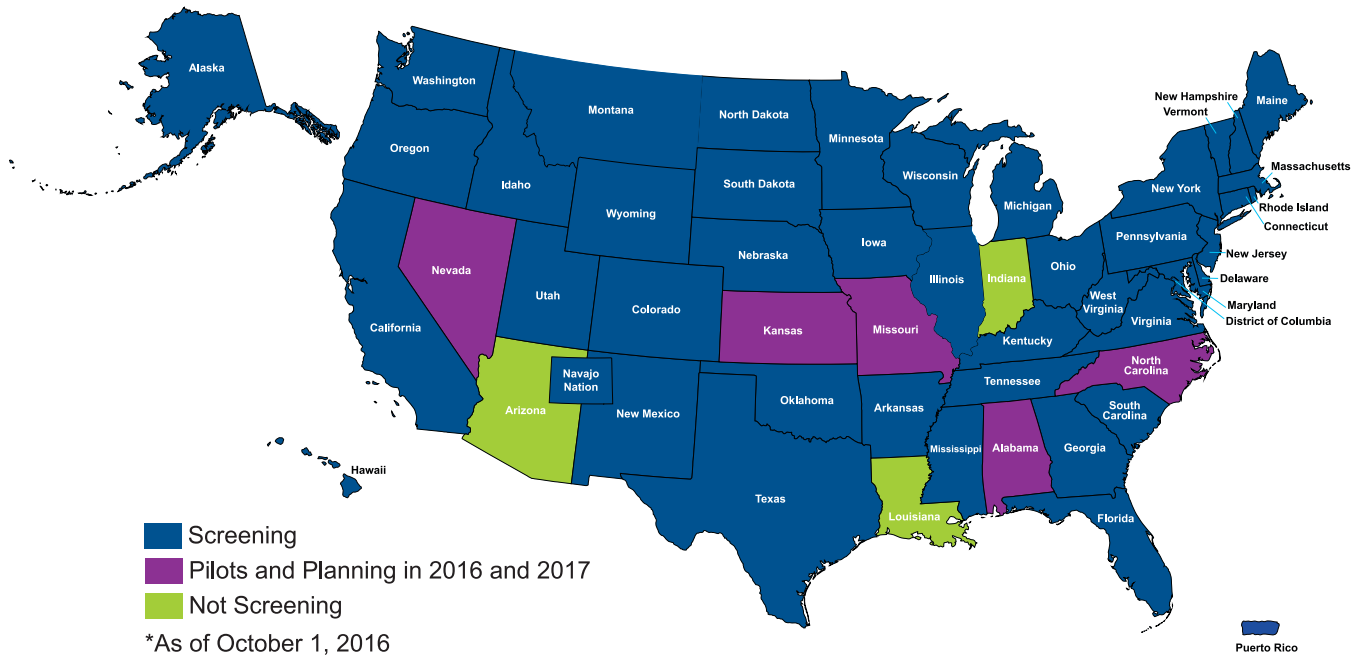
On June 25, 2015 before the IDF 2015 National Conference officially began, members of the PI community joined forces for a Rally for Newborn Screening for SCID in Louisiana. Over 200 IDF activists contacted public officials to let them know how important it is to implement a SCID newborn screening program in Louisiana. Since the conference, the state has taken some preliminary steps toward establishing a SCID screening program.

Seven new states began screening in 2015, Oklahoma, Virginia, South Carolina, Arkansas, Hawaii, New Hampshire and South Dakota making the total number of states screening for SCID 32. As of August 1, 2016, 42 states (88% of all US births) are screening for SCID. Puerto Rico, Tennessee, Idaho, Maryland, Kentucky and Georgia are the most recent states to begin screening, and there is an expectation that three additional states will begin screening by the end of 2016. The IDF SCID Newborn Screening Campaign blog, www.idfscidnewbornscreening.org, keeps the PI community updated. In 2015, there were 3,800 sessions on the blog.

Through public policy action and advocacy, IDF is a strong and influential voice on the issues affecting access to quality healthcare for patients with PI, including all treatments, sites of care and specialists, and improving quality of life.

SCID Newborn Screening: Current Status of Implementation Map*

42 States Currently Screening for SCID - 88% of all newborns in the U.S. are receiving SCID screening



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M. Elizabeth M. Younger, CRNP, PhD
Johns Hopkins University School of Medicine



IDF Nurse Advisory Committee 2015

Back row, from left: C. Duff; W. Blouin; D. Sedlak; L. Lyter-Reed; K. Epland. Front row, from left: L. Aro; L. Anastasia Schneider; D. Manning; M. Younger; M. Hintermeyer; L. Lentini. Not pictured: C. Dansereau; M. Dodds.

2015 IDF Core Service Corporate Sponsors

Because primary immunodeficiency (PI) diseases are rare, chronic conditions, continuity in our programs is one of the most important aspects of the services provided by our Foundation. Individuals living with PI – as well as their families – need to know that these services will be available throughout their lives. They need to know they can consistently count on the Immune Deficiency Foundation (IDF).

To ensure this constancy, IDF created the Core Service Program in the spring of 2000. As one of our most essential programs, it includes patient assistance resources, peer support, local patient meetings, volunteer activities, medical and scientific programs, medical meetings and exhibits, advocacy efforts, and survey research.

IDF's core services and strategic priorities are determined by an independent Board of Trustees, with input from the Medical Advisory Committee, based on the needs of patients.

Because of the Core Service Program, IDF is able to provide the educational materials and local programming to patients and families and healthcare professionals free of charge. This allows us to provide services and resources to those who need it, regardless of their ability to pay.

To continue to offer these indispensable core services to patients and medical professionals, IDF relies on the generosity of many for program funding. Our Core Service sponsors are dedicated organizations that make an enormous difference in the Foundation's ability to plan and provide long-term programming on behalf of the PI community. IDF greatly appreciates these sponsors and all others who make our mission possible.

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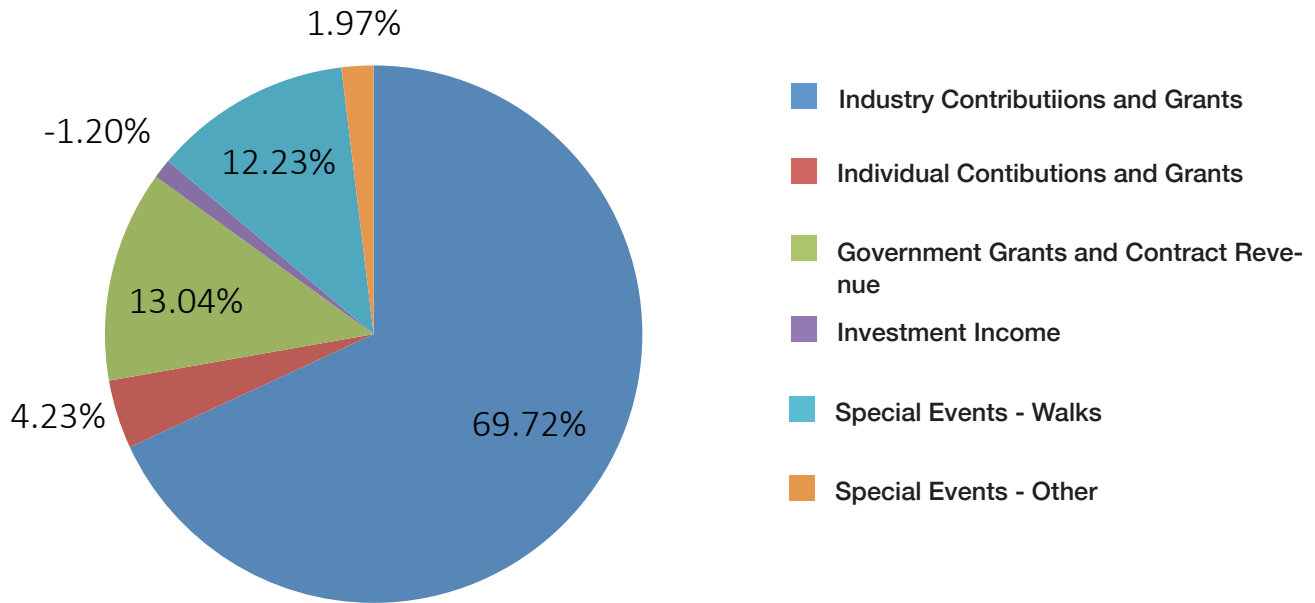
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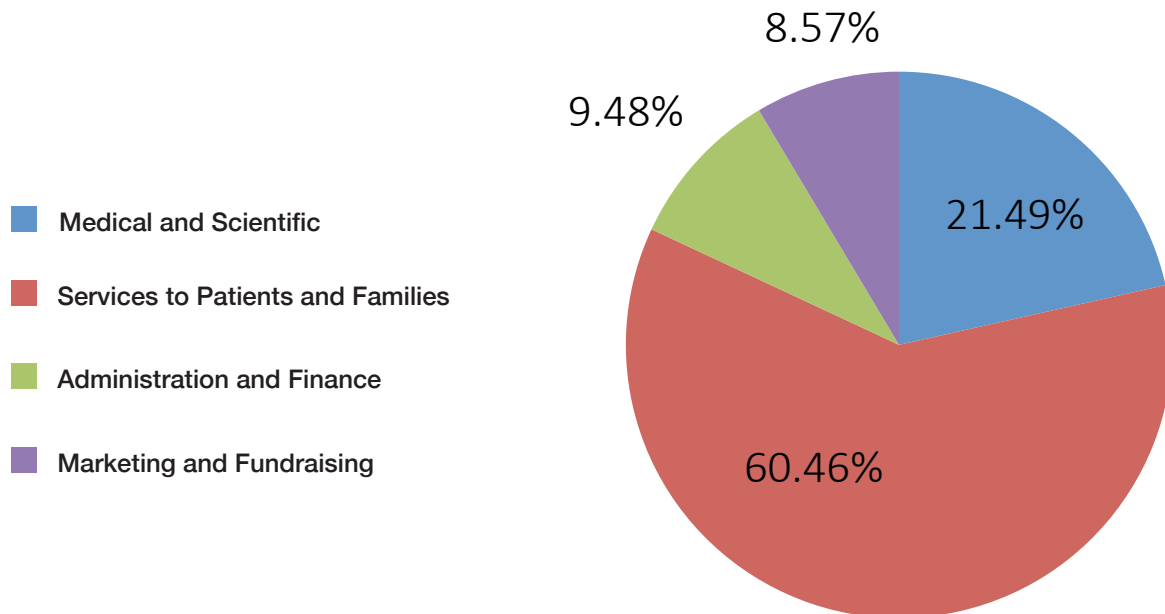
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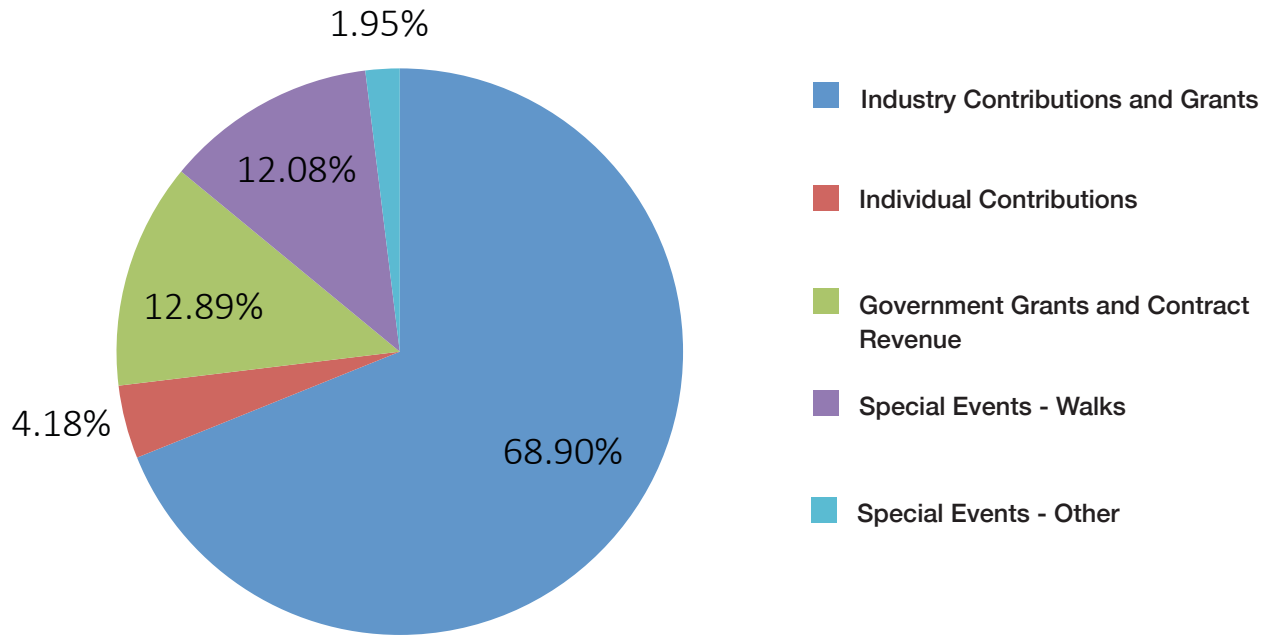
2015 Revenue with Investments



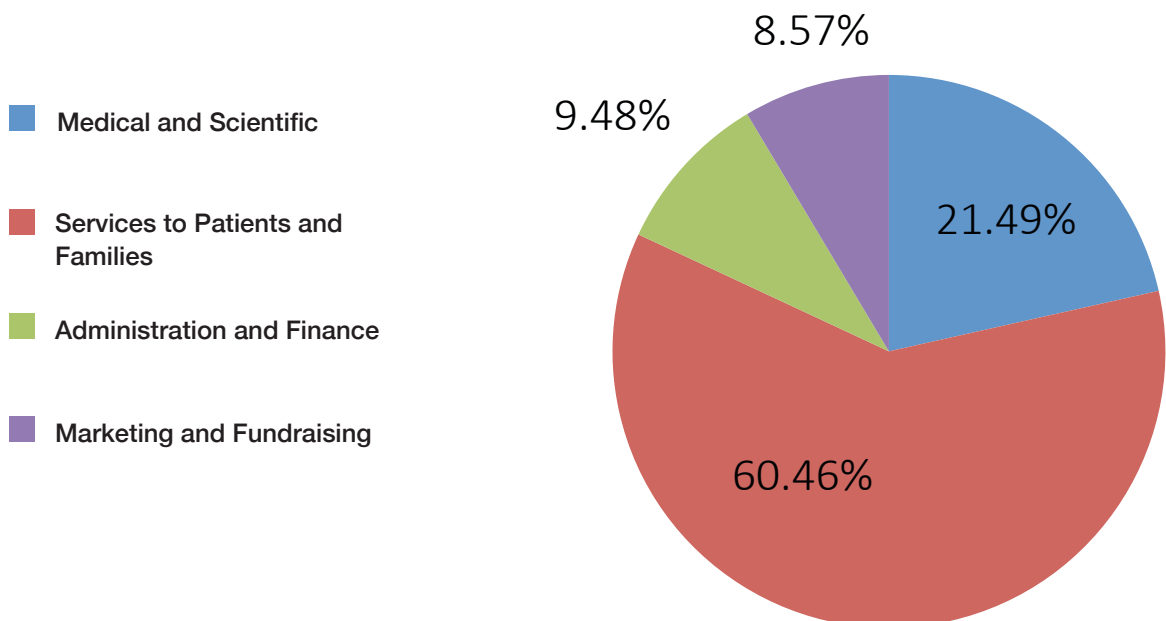
2015 Expenses



2015 Revenue without Investments



2015 Expenses



Statement of Activities & Changes in Net Assets for the Year Ended December 31, 2015

| | Unrestricted | Temporarily Restricted | Permanently Restricted | Total |
|---|---------------------|---------------------------|---------------------------|---------------------|
| PUBLIC SUPPORT AND REVENUE: | | | | |
| Public support: | | | | |
| Contributions and grants | \$ 5,128,863 | \$ 1,361,816 | \$ 12,000 | \$ 6,502,679 |
| Net assets released from restrictions | 1,676,133 | (1,676,133) | - 0 - | - 0 - |
| Total public support | <u>6,804,996</u> | <u>(314,317)</u> | <u>12,000</u> | <u>6,502,679</u> |
| Government grants and other contract revenue | <u>1,069,752</u> | <u>- 0 -</u> | <u>- 0 -</u> | <u>1,069,752</u> |
| Revenue: | | | | |
| Investment income (loss) | (97,606) | - 0 - | (513) | (98,119) |
| Other income | 205 | - 0 - | - 0 - | 205 |
| Special events | 727,187 | - 0 - | - 0 - | 727,187 |
| Total revenue | <u>629,786</u> | <u>- 0 -</u> | <u>(513)</u> | <u>629,273</u> |
| Total Public Support and Revenue | <u>8,504,534</u> | <u>(314,317)</u> | <u>11,487</u> | <u>8,201,704</u> |
| EXPENSES: | | | | |
| Program services: | | | | |
| Medical and scientific | 1,821,949 | - 0 - | - 0 - | 1,821,949 |
| Services to patients and families | <u>5,126,792</u> | <u>- 0 -</u> | <u>- 0 -</u> | <u>5,126,792</u> |
| | <u>6,948,741</u> | <u>- 0 -</u> | <u>- 0 -</u> | <u>6,948,741</u> |
| Supporting services: | | | | |
| Administration and finance | 803,799 | - 0 - | - 0 - | 803,799 |
| Marketing and fundraising | <u>726,820</u> | <u>- 0 -</u> | <u>- 0 -</u> | <u>726,820</u> |
| | <u>1,530,619</u> | <u>- 0 -</u> | <u>- 0 -</u> | <u>1,530,619</u> |
| Total Expenses | <u>8,479,360</u> | <u>- 0 -</u> | <u>- 0 -</u> | <u>8,479,360</u> |
| OTHER: | | | | |
| Transfer of unrestricted and permanently restricted funds | <u>21,794</u> | <u>- 0 -</u> | <u>58,525</u> | <u>80,319</u> |
| Total Expenses and Other | <u>8,501,154</u> | <u>- 0 -</u> | <u>58,525</u> | <u>8,559,679</u> |
| CHANGE IN NET ASSETS | 3,380 | (314,317) | (47,038) | (357,975) |
| NET ASSETS, BEGINNING OF YEAR | <u>6,752,999</u> | <u>1,735,533</u> | <u>47,038</u> | <u>8,535,570</u> |
| NET ASSETS, END OF YEAR | <u>\$ 6,756,379</u> | <u>\$ 1,421,216</u> | <u>\$ - 0 -</u> | <u>\$ 8,177,595</u> |

Statement of Functional Expenses for the Year Ended December 31, 2015

| | PROGRAM SERVICES | | | SUPPORTING SERVICES | | | Grand Total |
|---|------------------------|-----------------------------------|---------------------|----------------------------|---------------------------|---------------------|---------------------|
| | Medical and Scientific | Services to Patients and Families | Total | Administration and Finance | Marketing and Fundraising | Total | |
| Salaries | \$ 493,727 | \$ 1,410,058 | \$ 1,903,785 | \$ 297,162 | \$ 238,419 | \$ 535,581 | \$ 2,439,366 |
| Employee benefits | 48,694 | 128,955 | 177,649 | 51,892 | 26,885 | 78,777 | 256,426 |
| Payroll taxes, etc. | 40,740 | 114,028 | 154,768 | 25,140 | 21,431 | 46,571 | 201,339 |
| | 583,161 | 1,653,041 | 2,236,202 | 374,194 | 286,735 | 660,929 | 2,897,131 |
| Professional fees | 813,565 | 1,167,839 | 1,981,404 | 192,995 | 77,246 | 270,241 | 2,251,645 |
| Training, conference, conventions, & meetings | 81,772 | 1,352,500 | 1,434,272 | 5,576 | 129,370 | 134,946 | 1,569,218 |
| Travel | 64,129 | 255,832 | 319,961 | 7,059 | 38,979 | 46,038 | 365,999 |
| Awards and grants | 64,412 | 33,000 | 97,412 | - 0 - | - 0 - | - 0 - | 97,412 |
| Occupancy | 45,337 | 192,942 | 238,279 | 55,027 | 24,400 | 79,427 | 317,706 |
| Insurance | 4,174 | 15,214 | 19,388 | 3,739 | 1,924 | 5,663 | 25,051 |
| Printing and publications | 89,814 | 145,407 | 235,221 | 8,285 | 16,145 | 24,430 | 259,651 |
| Telephone | 8,225 | 30,979 | 39,204 | 17,034 | 5,516 | 22,550 | 61,754 |
| Postage and shipping | 21,611 | 106,775 | 128,386 | 7,578 | 30,333 | 37,911 | 166,297 |
| Supplies | 9,660 | 54,476 | 64,136 | 87,022 | 16,314 | 103,336 | 167,472 |
| Rental and maintenance of equipment | 12,800 | 37,513 | 50,313 | 29,848 | 12,023 | 41,871 | 92,184 |
| Miscellaneous | 3,000 | - 0 - | 3,000 | 2,020 | 10,079 | 12,099 | 15,099 |
| Advertising | 5,932 | 32,122 | 38,054 | 185 | 47,988 | 48,173 | 86,227 |
| Dues and subscriptions | 7,519 | 20,051 | 27,570 | 4,938 | 26,088 | 31,026 | 58,596 |
| | 1,815,111 | 5,097,691 | 6,912,802 | 795,500 | 723,140 | 1,518,640 | 8,431,442 |
| Depreciation and amortization | 6,838 | 29,101 | 35,939 | 8,299 | 3,680 | 11,979 | 47,918 |
| | <u>\$ 1,821,949</u> | <u>\$ 5,126,792</u> | <u>\$ 6,948,741</u> | <u>\$ 803,799</u> | <u>\$ 726,820</u> | <u>\$ 1,530,619</u> | <u>\$ 8,479,360</u> |

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IDF Walk for Primary Immunodeficiency Teams 2015

TEAM NAME

| | | | |
|--------------------------|--|--|---|
| #SophiaStrong | Specialtiy Infusion Services | Jacob's Ninja Turtles | McMahon |
| #teamHailey | Cynthia's CVID Gang 2015 | JDCH Division of Allergy and Immunology | Megan's Herd |
| AAIA | Dahlia Lovers | Jenny's Journey | MGH-PID |
| AAIR of Charlotte | Dink's Team for PI Awareness | Jessica's Jamboree | Miah's Motivators |
| ABBY'S ENFORCERS | Don't Stop Beelievin! | Jodi's Team | Michelle |
| Accredo Health | Dorian's Dream | Josephs Crew | Michelle's Team |
| Addison Amelia | Dowdle Herd | Josie's Helping Hand | Midwest Immunology Clinic |
| Aj's Team | DPHSCheerleaders | Judy's Jammers | Mighty Mighty Mason |
| Alanna's Team | Dr. Tichenor's Team | KAELA | Milena's Marchers |
| Albert's Angels | Drew & Mary Strength in Numbers | Kaitlyn's Palmetto Zebra's | Minions |
| All About Audrey | ENT and Allergy | Karen's Zebras | Miracle Walker |
| Allee Oop | Erin's Antibodies | Kari's Krusaders | MN-JLJ's team |
| Alphabet Soup | Family Love | Kavya's Krew | Money Team |
| April's Advocates | Fontenot Zebras | kaylins team | nancy's walkers |
| April's Amigos | GA Communication Team | Kedrion Team | NAPLES FL Avengers |
| AT HOME INFUSION | GaleForce | Keene kickers | neon zebras |
| Awesome Dawson | Gammaked Gazelles | Keeping Up With Kate | new girls on the block |
| Bad Blood | Geaux Jo | Kelly Rocks | NSU Accounting Club |
| Becky's Brigade | Gobs, etc | Kelly's Krew | Octapharma Plasma |
| Beige | GoJoe | Kickin' it for Kate | Option Care Philly |
| Bio Rx | Good's Gang | Kimber's Pride | Pentec Health |
| BioLife Plasma Services | Granted Immunity | King 'O the Cats | PI Walkers |
| Biotest | Grants Guardians | Kruse's Kew | PI Warriors |
| Boston Strong | Grateful Graceful Walkers | Larsons | Princess Zebra |
| Brandi's Zebra Zoo | Gulf Coast Regional Blood Center | Laurajan's Hemoglobin Trotters | Purple Zebras |
| Brightstar | Gus's Race Car Dudes | Laura's Amazing Antibodies | Purpleperse |
| Brockin' Zebras | Haemonetics | Laura's Awesome Zebras | Ralph Kaeser Memorial Team |
| Bryce's Brigade | Hafetz and Associates Holiday Team | LB3 | Rashann's Stampede |
| B's ZZ Crew 2 | Halper's Helpers | Leapin Lizzards | Rayden's Raiders |
| Bucks Zebra's | Hardt's Heros | Lee's Herd | Reisman Rocks |
| By-the-Sea | Harper's Team | Lorna J's Making Strides | Rhino |
| Caiden's Crew | Hart & Soul | Love For Lucas | Rhodes of Hope |
| Carolina Zebra's | Heidi's Heros | Love Wins | ROO'S GAMMA RAYS |
| Charlotte Zebras | Higgins Crew | Lucas's Stars | Ryan's Gang |
| Chelsee's Herd | Horizon Pharma Home Team CGD | Lurie Children's | Ryan's Pride |
| Christina's Crew | Houston THINK Zebra! | Maddie's Herd | Ryan's Rebels |
| Chuck's Champs | Hypogamma Goblins | Madeline Rose | Rylan's Zoomin' Zebras |
| Clara | Incredible Zebras | Madi Hafetz's LA Team | Samantha's Herd |
| Clare's Team | Intouch Solutions | Magnificent Millers | Sandee Plastics |
| Cleveland Clinic Florida | Isa is a Fighter | Magnum PI Krew | Santa Monica Boys and Girls Club, Pacific Branch |
| Collinge | Isabella's Immunogladiators | Maish Family | Sarah's Journey, Together we can beat PI |
| Coping with PI in PA | It's an Ashley Thing | Mak Zebras | Schwarz Force |
| Corinthian Crusaders | iviG UNIT | Mandy's Immune Platoon | SCID (Seriously Cool Immune Deficient) Kids |
| Courageous Zebras | Jack and Jill Associates, The Woodlands Texas | Maranda | SCID Stripes |
| CSL Behring | | MARC13 | ScribeAmerica Houston |
| Curly Girl Club | | Mark the Shark | Sean Deal |
| CVS Caremark I Coram | | Maverick's Mission | |
| | | Max's Crew | |

IDF Walk for Primary Immunodeficiency Teams 2015

| | | | |
|---------------------------------|---------------------|-----------------------------|--------------------------|
| See Jane Walk | Team Gabby | Team Penna | University Hospitals |
| Seth's 2015 IDF Walk Team | Team Gamma Girl | Team Rainbow Dash | Allergy I Immunology |
| Seymour Zebras | Team Gelfano | Team Rath | US Bioservices |
| SmolaSwag | Team Ginger | Team Risdal | Vada Strong |
| Soleo Health | Team Green | Team Rossi | Veronica |
| Spud's Superstars | Team Grifols | Team Sam | Walk for PI in Ukiah |
| Stef's Chicks | Team Halloran | Team Sebastian | Walk Reilly |
| Stephen's Strollers | Team Hameed | Team Slack | WALK TO A DIFFERENT |
| StormySky | Team Hanna | Team Sophie | HOOFBEAT |
| Stripes R US | Team Hope | Team Superman | Walking for David Carey |
| Strolling Singers | Team IVIG and Tonic | Team Superstripes | and Jeanne Hindin |
| Summa Home Infusion | Team J | Team Tara | Walking on the Wild side |
| SuperWyatt | Team J Dub | Team Tessman | Warriors for Alek |
| Take the Lead with Ethan & Reed | Team Jacob | Team Tia | Willen's Walkers |
| Taylor's Dazzle | Team Janaiyah | Team Vada | Wilson's Wonders |
| Teagan's Zeal | Team Jared | Team Vega | WSPC Center For Allergy |
| Team Addie and Kenzie | Team Jensen | Team Waya | & Immunology |
| Team Aden | Team Jordan | Team Wonder | Xander's Zebras |
| Team Aidan | Team Justin | Team Wyatt | X-Linked Agammaglobu... |
| Team AIR | Team katerinia | TeamFladFam | Wait... What? |
| Team Alejandrino | Team Kaysen | TeamIlgG | Zak Attack |
| Team Alicia | Team Kegan | Teresa's Troopers | Zander's Zebras |
| Team Bammes | Team Kelly G | Texas Children's Walkers | Zebra Beats |
| Team Barb | Team Lewin | The BA-Team | Zebra Clan |
| Team Baxalta | Team Liam's Fight | The Daniel Team | Zebra Fever |
| Team Baylee | Team Liana | The Elite Four | Zebra Medics |
| Team Ben | Team Lindsay | The Gargi | Zebra Mom |
| Team BiocureRx | Team Lombardi | The Heat | Zebra Princess Layla |
| Team Biofusion | Team Lukas | The Heat | Zebra Warriors |
| Team Boyle | Team MacKenzie | The Low Down on PIDDs | Zebra_Warriors2 |
| Team BPL | Team McDonnell | The Sub-Q-Tees | Zebra_Girls2 |
| Team Brooklyn | Team McKenzie | The Toothless Q Tips | ZEBRAS |
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| Team Casey | Team Meuers | The Zebrateers | Zebra's Of The Northeast |
| Team CHOP | Team Naughton | Three IgG Zebras | Zens Zebras |
| Team Chris | Team Naveyah | ToKaVi | Zeta Beta Tau |
| Team Christian | Team Nawrotzki | Toni's Globulins | Zombie Squad |
| Team Cole | Team Noah | Tracy's Troops | Zydeco Zebras |
| Team CuKo | Team Olivia | Travis | |
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