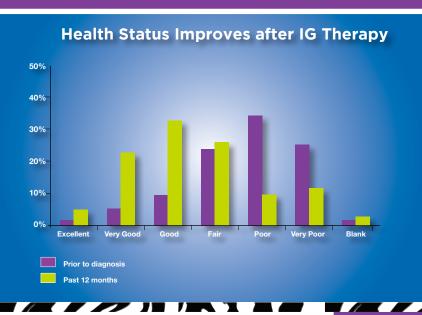


# Improving Health. Powering Research.









2014 Annual Report



Immune Deficiency Foundation

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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

It is with great pride we report that the Immune Deficiency Foundation (IDF) continues to grow and help thousands of individuals and families living with primary immunodeficiency (PI) diseases each year. Our national conferences, retreat weekends, and patient meetings throughout the U.S. provide incredible educational opportunities for individuals and families. Our full spectrum of educational publications, the hallmark of IDF's efforts, have been heralded as the best patient resources about PI in the world. To provide easier access to more people and enhance how individuals manage their health, our online presence and resources have evolved tremendously.

In 2014, IDF moved forward with a bold agenda to innovate how technology could be used to help our community, and to increase our online presence. From IDF ePHR, our electronic personal health record, to our social networks, these unique technologies have given us more ways to engage with and help the PI community. We are reaching more patients with tools designed specifically for them. More than ever before, our community is plugged in and want to get involved, and our online resources allow them to do just that.

IDF has always focused on the patient using innovative approaches to help give researchers insight into the patient experience. In 2014 we developed a revolutionary research network focused on PI—PI CONNECT, the IDF Patient-Powered Research Network. 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 that will help researchers find answers, ultimately individualizing treatment and providing better outcomes for patients. IDF received a grant from Patient-Centered Outcomes Research Institute (PCORI) to develop PI CONNECT, which brings together patient data from IDF ePHR with clinical data from the United States Immunodeficiency Network (USIDNET), the only national patient-consented registry for PI. And to truly bring patients into the research conversation, patients can let their voices be heard in the PI CONNECT Research Forum. Bringing together this information and the patient voice holds great promise to provide researchers further insights about the diagnosis and treatment of primary immunodeficiency, ultimately helping to improve quality of life for patients.

Individuals become a part of PI CONNECT through IDF ePHR, our electronic personal health record, which also underwent a major transformation in 2014 providing our users with the latest advancements in health record system management. The state-of-the-art platform 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.

The hub of our community remains the IDF website, www.primaryimmune.org, which saw record activity in 2014 with more than double the amount of visitors than 2013. Our popular social networks, IDF Friends and IDF Common Ground, received major updates in 2014, making it even easier for individuals and caregivers to connect in private communities, discuss their personal experiences and learn from each other.

With so many accomplishments in 2014, our digital impact is only part of the remarkable efforts underway in advocacy, education and research. Please take a moment to reflect on all achievements of the Foundation over the past year detailed in this Annual Report. Thank you to all of those who made it possible. Each member of our community plays a critical role in helping us grow, evolve and make a difference in the lives of those living with primary immunodeficiency.

Sincerely,

Marcia Boyle

IDF President & Founder

Marcin 7. Byl-

John Seymour, PhD, LMFT

Chair, IDF Board of Trustees









# 2014 Year in Review

Reflecting on the past year, it is always helpful to review ongoing programs and activities to evaluate the impact IDF truly has had while working on behalf of the primary immunodeficiency community in 2014.



**IDF ePHR**, the electronic personal health record developed for individuals and

families living with primary immunodeficiency diseases (PI), received major enhancements in 2014, complete with a new, state-of-the-art system to transform how individuals manage their health. This one central location offers the latest advancements in health record system management, featuring convenient, user-friendly tools to help individuals with PI live healthier lives. IDF ePHR keeps health information safe, secure and private at no cost to users. Hundreds of individuals and caregivers are now tracking health information with IDF ePHR, and the number of users continues to grow.



PI CONNECT, the new IDF Patient-Powered Research Network, connects the information users have consented to share from their IDF ePHR with the United States Immunodeficiency Network (USIDNET) patient-consented registry, which contains de-identified clinical data on several thousand individuals with PI. PI CONNECT became a reality after IDF was approved for a funding award from the Patient-Centered Outcomes Research Institute (PCORI) in December 2013. PI CONNECT is part of PCORnet: the National Patient-Centered National Clinical Research Network, which aims to advance the shift in clinical research to patient-centered studies, giving individuals "a seat at the research table." Bringing together this information through PI CONNECT gives researchers a better idea of the patient experience. PI CONNECT along with all networks in PCORnet has formed a national resource that boosts the efficiency of health research.

# 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). 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 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 individuals with PI. Present enrollment has surpassed 4,000 participants. In 2014, the USIDNET Steering Committee published the manuscript USIDNET: a strategy to build a community of clinical immunologists in The Journal of Clinical Immunology, with USIDNET Steering Committee Member, PI CONNECT Principal Investigator, and IDF Board Member, Kathleen Sullivan, MD, PhD of Children's Hospital of Philadelphia as first author.

#### **Patient Services**

As a national patient organization, education is central to our mission and each year, IDF hosts education meetings throughout the country. IDF believes it is imperative to increase efforts to partner with healthcare professionals in geographic regions to reach more individuals with primary immunodeficiency diseases (PI) and enhance the content of the meetings.

#### **Patient Education Programs**

In 2014, IDF hosted 23 Education Meetings and Family Conference Days, which are daylong meetings where local experts present medical and life management sessions to adults. The Family Conference Days are Education Meetings with the addition of a youth program for ages 5 and up. Through these meetings, IDF reached 1,634 individuals.

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#### **IDF Get Connected Groups**

IDF Get Connected Groups provide an opportunity for individuals to network and receive support in their local community. In 2014, 29 Get Connected Groups, hosted by IDF volunteers, were held in 13 cities in 10 states. Through these meetings, IDF reached a total of 214 individuals.



#### **IDF** Retreats

IDF Retreats are weekend gatherings designed with everyone in the primary immunodeficiency community in mind.
Individuals with PI, parents, siblings, children and partners were

encouraged to attend and learn how to develop better approaches to living with PI. Two IDF Retreats were hosted in 2014, one in Atlanta, GA with 230 attendees from 24 states, and another in Portland, OR with 222 attendees from 17 states and Canada. Attendees learned the latest information about the treatment and management of PI from leading physicians and healthcare professionals. The IDF Retreats were a big success bringing together more than 450 people from across the country.

#### **IDF** Teen Program

The IDF Teen Program contains many elements and ways to reach teens in the best ways possible. The period of transition from adolescence to adulthood is a difficult time for most individuals. However, those affected by PI can have an even more complicated time. Throughout all the components of the Teen Program 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. The IDF Teen Program currently has 140 teens participating.

#### **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 2014, IDF Teen Escape weekends were held in Cleveland, OH and Garden Grove, CA with a total of 173 individuals attending.

#### **IDF Young Adult Program**

In conjunction with the IDF Teen Escapes, two Young Adult Weekends provided an opportunity for individuals, ages 19-35, to learn about IDF programs and managing PI. They networked with others and shared their experiences.

#### **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 IDF Walk for PI. Overall, thousands of volunteer hours are donated to IDF each year!

In 2014, peer support volunteers offered personalized encouragement and advice to 508 individuals or family members living with PI in addition to spending thousands of hours supporting others on IDF Friends. An increasing number of individuals of all ages want to support the mission of IDF.

## **IDF Plasma Partners Program**

The IDF Plasma Partners Program creates awareness about PI diseases and shows the intertwined relationship between individuals with PI, plasma donors and employees in plasma collection centers throughout the U.S. IDF arranges plasma center visits for individuals and family members living with PI, where they can gain a better understanding of the importance of plasma donation. Often they are the first person 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 individuals with PI through the plasma collection process. The companies that participate in the IDF Plasma Partners Program help raise funds and awareness for IDF. In 2014, our volunteer network helped spread awareness by distributing thousands of pieces of educational materials and spoke to 3,860 people during 75 visits to plasma centers.

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. Because the health of persons with PI and plasma businesses are so connected, IDF considers each company involved a partner in improving the lives of patients. Thank you to our Plasma Partners:

BioLife Plasma Services
Biotest Plasma Centers
CSL Plasma
Grifols

## **IDF Academic Scholarship Programs**

When there is adequate support, IDF awards scholarships to undergraduate students living with PI who plan on completing their post-secondary education. The Eric Marder Scholarship Program was open to individuals with a PI and was intended for undergraduate students attending or entering college or a technical training school. The Varun Bhaskaran (WAS) Scholarship Program was open to undergraduate or graduate students living with Wiskott Aldrich Syndrome (WAS). For the 2013-2014 school year, \$38,000 in scholarships were awarded, 36 scholarships through the Eric Marder Scholarship Program, and one from the Varun Bhaskaran Scholarship Program.

# **Patient Advocacy Program**

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 2014, IDF's patient advocacy services helped fill the need for 6,461 requests from individuals and families seeking education, information and assistance, which is 1,240 more than 2013. The top three reasons that individuals 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. We also worked with individuals with PI, providers, and insurers to advocate for an appropriate updated medical policy for IVIG.



#### **Health Professional Outreach**

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

#### **IDF Medical Advisory Committee**

The IDF Medical Advisory Committee (MAC) is comprised of prominent immunologists from throughout the country who support the mission of the IDF through the development of science based standards for diagnosis and care for individuals with PI.

In 2014, members of the MAC presented at IDF local Education Meetings and IDF Retreats. They also published the article "Recommendations for live viral and bacterial vaccines in immunodeficient patients and their close contacts" in *The Journal of Allergy and Clinical Immunology*, April 2014. Each year, members of the MAC play a valuable role when addressing health insurance issues that concern the PI community, and they regularly help answer questions from individuals and families as well as other healthcare professionals.

#### **IDF Nurse Advisory Committee**

The IDF Nurse Advisory Committee (NAC) works to improve the quality of healthcare and education provided by nurses who care for those living with PI and to increase awareness of PI through professional education and outreach. In 2014, the NAC participated in innovative projects to help improve the quality of healthcare and education provided by nurses caring for those with PI here in the U.S. and internationally. Members presented at IDF local Education Meetings and IDF Retreats, answered patient questions, and represented IDF at medical conferences. The NAC also created a patient-friendly version of the MAC vaccine guidelines. The IDF Online Course for Nurses: Primary Immunodeficiency Diseases and Immunoglobulin Therapy underwent a complete review and assessment by IDF NAC members. In total the course has had 2,104 registrants, and 837 certificates have been issued.

#### **Consulting Immunologist**

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 2014, 77 clinicians used the Consulting Immunologist Program, and the program continues to be well-received.

# 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 2014, visiting professorships were held in 10 locations, including Mayo Clinic, Rochester, MN, University of Michigan Medical School, St. Luke's Children's Hospital, Children's Mercy Hospital and Clinics, North Shore Long Island Jewish Health System, Medical College of Wisconsin, Mass General Hospital/Harvard, UCSF Benioff Children's Hospital, Wake Forest, and University of Texas Medical Branch (UTMB). The number of attendees grew from 1,100 in 2013 to over 1,300 in 2014.

#### **Medical Meetings & 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 care for individuals with PI, to discuss educational opportunities, and to distribute educational literature and discuss IDF resources. In 2014 IDF attended five medical exhibits around the U.S. with over 3,700 attendees, including the American Academy of Allergy Asthma and Immunology (AAAAI), Clinical Immunology Society (CIS), Infusion Nurses Society (INS), Immunoglobulin National Society (IgNS) and American College of Asthma, Allergy & Immunology (ACAAI).

#### IDF presented scientific posters for:

- International Patient Organization for Primary Immunodeficiencies (IPOPI)
- Immunoglobulin National Society (IgNS)
- European Society for Immunodeficiencies (ESID)
- International Nursing Group for Immunodeficiencies (INGID)

## **Public Policy and Advocacy**

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

# **IDF Advocacy Day 2014**

The 2014 IDF Advocacy Day on Capitol Hill gathered nearly 50 participants that met with 109 legislative offices in support of The Patients' Access to Treatment Act (PATA), 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. This bipartisan legislation that will help ensure patients with chronic, disabling and life threatening conditions to access 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.



## SCID Newborn Screening in States

IDF continues to be the grassroots leader in working to have newborn screening (NBS) 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. As of January 1, 2015, 25 states were screening. As of July 1, 2015, 33 states (75% of all US births) are screening and between six and nine states are expected to begin screening by the end of 2015. The SCID Newborn Screening Blog keeps the community updated as we work to implement SCID Newborn Screening in all 50 states. In 2014, there were 22 blog posts with more than 3,800 sessions.

#### 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 CMS to help monitor and promote the project. Nearly 1,000 beneficiaries enrolled from August 1-December 31, 2014.

#### Affordable Care Act (ACA) Implementation

IDF works to keep patients and families living with PI upto-date about the Affordable Care Act (ACA), also known as the healthcare reform law. IDF has produced educational videos, updated the IDF Insurance Toolkit, developed various articles as part of IDF communications, worked with other patient organizations, and commented on specialty tier coinsurance legislation and various federal proposed rules regarding transparency, restricted formularies, and essential health benefits.

#### **Blood Safety**

Through American Plasma Users Coalition (APLUS), IDF expressed support for the HHS proposed policy change from a lifetime ban on donations to one year only if the FDA fully funded a robust hemovigilance monitoring system. HHS adopted the one year ban and is creating a hemovigilance monitoring system.

#### **Private Insurance**

IDF was successful in working to solve problems with major insurers in 2014. IDF and the companies worked together to produce positive outcomes for those living with PI. In addition, IDF placed two articles in payer oriented publications outlining the need to work together with patient organizations and detailing the risks of restricted formularies and inadequate networks.

#### **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. Biosimilars are medicines that are highly similar but not identical to biological medicines. Noting the need for the voice of individuals living with PI to be heard in the debate over biosimilars, IDF organized a national patient organization coalition, Patients for Biologics Safety and Access (PBSA), to provide that voice by meeting with the FDA, sending comment letters to FDA, informing Congress and working with the media. Twenty-two national patient organizations are members of PBSA.

#### Survey Research

IDF national patient surveys provide crucial insight into the personal impact of primary immunodeficiency diseases (PI) and help 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. Survey Research has provided active assistance in the following areas:

- XLA Survey, Published in *The Journal of Clinical Immunology*
- Women's Reproductive Health Survey, Published in The Journal of Clinical Immunology
- Pediatrician Survey, Published in Clinical Pediatrics
- Poster Abstract Based on 2012 IDF National Patient Survey, Presented at the American Academy of Allergy, Asthma & Immunology
- Poster Abstract, Presented at the American College of Chest Physicians
- Health Care Reform's Impact of Patients with Primary immunodeficiency Survey
- Physician "PI Baseline" Survey

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

#### Communications

IDF communications manages the development and production of IDF resources, both print and online, to provide vital information to individuals and families living with PI and healthcare providers. By expanding and engaging more people, IDF can connect more individuals and family members seeking answers and looking for others who understand—ultimately helping to improve their quality of life.

## Newsletter and E-newsletter

In 2014, IDF communications continued to update and inform our community with our newsletter, IDF ADVOCATE, published three times a year (circulation of 32,500), and a monthly e-newsletter, Primary Immune Tribune (circulation of 19,000).



#### **Social Networks**





Both of IDF's social networks, IDF Friends and Common Ground, were completely redesigned and built on new platforms. Launched in the beginning of 2014, both networks have received a great deal of positive feedback and a spike in usage. The networks are mobile-responsive, feature new user-friendly layouts, and are 100% private, visible only to members—no one may access any site content without creating an account. Additionally, IDF rolled out the new Chat and Instant Message modules.

#### Social Media

IDF reaches many members of the community through social media, and our numbers grew in 2014 with 7,467 Facebook likes and 1,120 Twitter followers. In a year's time, IDF Instagram followers jumped up to 166 in 2014 from 39 in 2013.



#### **IDF** Website

The IDF website is often the first place individuals living with PI turn when they receive a diagnosis. This is largely due to the many valuable web-based resources IDF offers. The most visited pages on primaryimmune.org are on specific disease types such as Selective IgA Deficiency, Common Variable Immune Deficiency and IgG Subclass Deficiency, as well as treatment options. Redesigned in 2013, the enhanced, mobile-responsive site receives more than 50,000 sessions per month. The content is regularly updated, and the site features an easy-to-use layout and menus. The traffic to our website more than doubled, generating 750,663 of session views in 2014.

#### **IDF** Blog

The IDF blog features news and updates about various topics that affect the PI community. In 2014 there were 99 blog posts.

#### **IDF Videos**

IDF videos is the hub to access all of IDF's video channels. The majority of content is generated by individuals with PI. All IDF videos combined have been watched more than 300,000 times. We have channels dedicated to:

- IDF Advocacy
- IDF CommonGround
- IDF ePHR
- IDF General Videos
- IDF Reel Stories

#### Awareness Month and World PI Week

In April, 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. During Awareness Month and WPIW, IDF secured press opportunities and highlighted the importance of vaccines based on the IDF Medical Advisory Committee article, "Recommendations for live viral and bacterial vaccines in immunodeficient patients and their close contacts," which appeared in the April 2014 edition of *The Journal of Allergy and Clinical Immunology*. 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.

#### Whack-A-Germ App

One of the most popular games from the IDF Arcade, Whack-A-Germ is now an app. In the Whack-A-Germ app, players get the satisfaction of whacking the germ while watching out for the friendly T-cells and phagocytes. The app is available for free from Google play (Android) and the iTunes store (iOS). Search for "IDF Game." Our online IDF Arcade, filled with educational games for children of all ages, is still going strong and has been visited 1,318 times.



# WALKE PRIMARY IMMUNODEFICIENCY

#### IDF Walk for Primary Immunodeficiency 2014

IDF Walk for Primary Immunodeficiency supports vital IDF programs and services, and increases awareness about primary immunodeficiency across the country. In 2014, a gross revenue of \$713,000 was generated, representing a year to date increase of 60%. The total number of donations increased by 2,078 at a total of 4,984 donations. In 2014, over 3,000 walkers and 337 teams participated at one of six sites across the country. Locations included Boston, Greater Chicago, Houston, Los Angeles, New York City and Philadelphia. We also have a Nationwide Virtual Walk that allows our community to support the walk program from wherever they live.

The IDF Order of the Zebra, which is our top fundraising club, was first implemented in 2014. The order is the elite group of fundraisers whose efforts make an extraordinary impact on the success of IDF Walk for Primary Immunodeficiency. 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 2014, IDF had more than 81 members raise over \$1,000 and become a part of the club.

There were over 63,000 unique sessions on www.walkforPl.org, and the IDF Walk for Primary Immunodeficiency Facebook page gained 1,361 fans. Engaged constituents also promoted the walk through Facebook events for each walk across the country.























# Leadership

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Committee Vice Chair

Amy Walsh



#### IDF Board of Trustees 2015

Back row, from left: J. Seymour; B. Rath; T. Halper; J. Boyle; C. Lage; M. Boyle; R. Low; J. Smith; S. Fietek; J. Buckberg; S. Kaufman; Y. Shorten. Front row, from left: K. Sullivan; M. Hurley, R. Buckley, B. Ballard; C. Demaret; A. Walsh. Not pictured: D. Bell and R. LeBien

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E. Richard Stiehm, MD UCLA School of Medicine

Troy Torgerson, MD, PhD Seattle Children's Hospital

James Verbsky, MD, PhD Medical College of Wisconsin

Jerry Winkelstein, MD



#### IDF Medical Advisory Committee 2015

Back row, from left: F. Bonilla; M. Ballow; T. Torgerson; E. Stiehm; M. Conley; R. Fuleihan; H. Lederman; F. Candotti; S. Holland. Front row, from left: J. Routes; H. Ochs; C. Cunningham-Rundles; W. Shearer; R. Buckley; J. Puck; M. Boyle. Not pictured: Z. Ballas; R. Blaese; A. Filipovich; T. Fleisher; L. Forbes; E. Gelfand; V. Hernandez-Trujillo; H. Malech; S. Miles; L. Notarangelo; J. Orange; K. Sullivan; S. Rosenzweig; J. Verbsky; J. Winkelstein.

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**William Blouin, MSN, ARNP, CPNP** – Vice Chair Miami Children's Hospital

Loris Aro, RN

Sussman & Associates Immunology

Maggi Dodds, RN, MS, CPNP

Baylor College of Medicine/Texas Children's Hospital

Kristin Epland, FNP-C

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The Children's Hospital of Philadelphia

Debra A. Sedlak, CPNP, MSN

Duke Medicine

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; T. Rayburn.









# 2014 IDF Sponsors

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.
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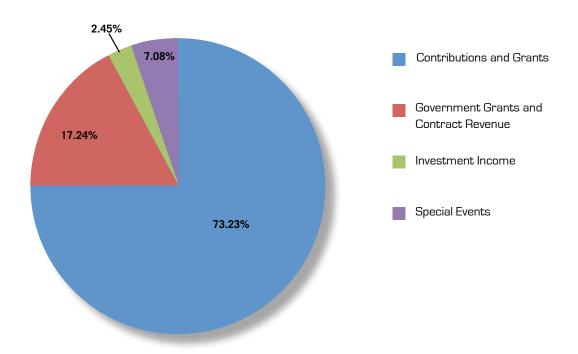
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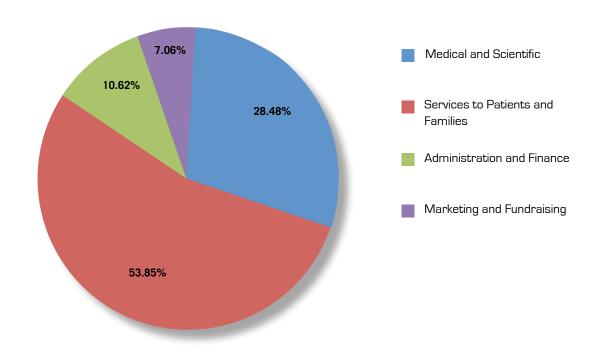
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2014 Revenue



2014 Expenses



# Statement of Activities and Changes in Net Assets For the Year Ended December 31, 2014

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
PUCLIC SUPPORT AND REVENUE:				
Public support:				
Contributions and grants	\$3,672,747	\$1,618,009	\$4,183	\$5,294,939
Net assets released from restrictions	1,412,781	(1,412,781)	- 0 -	- 0 -
Total public support	5,085,528	205,228	4,183	5,294,939
Government grants and other contract revenue	1,246,185	- 0 -	- O -	1,246,185
Revenue:				
Investment income	175,450	- O -	1,443	176,893
Other income	- 0 -	- O -	- 0 -	- 0 -
Special events	512,206	- 0 -	- 0 -	512,206
Total revenue	687,656	- 0 -	1,443	689,099
Total Public Support and Revenue	7,019,369	205,228	5,626	7,230,223
EXPENSES:				
Program services: Medical and scientific	1,793,055	- 0 -	- O -	1,793,055
Services to patients and families	3,390,462	- 0 -	- 0 -	3,390,462
	5,183,517	- 0 -	- 0 -	5,183,517
Supporting services: Administration and finance	668,537	- 0 -	- 0 -	668,537
Marketing and fundraising	444,629	- O -	- O -	444,629
	1,113,166	- 0 -	- 0 -	1,113,166
Total Expenses	6,296,683	- 0 -	- 0 -	6,296,683
CHANGE IN NET ASSETS	722,686	205,228	5,626	933,540
NET ASSETS, BEGINNING OF YEAR	6,030,313	1,530,305	41,412	7,602,030
NET ASSETS, END OF YEAR	\$6,752,999	\$1,735,533	\$47,038	\$8,535,570

# Statement of Functional Expenses For the Year Ended December 31, 2014

	PROGRAM SERVICES			SUPPORTING SERVICES			
	Medical and Scientific	Services to Patients and Families	Total	Administration and Finance	Marketing and Fundraising	Total	Grand Total
Salaries	\$446,907	\$1,161,964	\$1,608,871	\$271,544	\$177,871	\$449,415	\$2,058,286
Employee benefits	35,200	119,661	154,861	48,697	19,900	68,597	223,458
Payroll taxes, etc.	38,980	95,621	134,601	17,789	15,229	33,018	167,619
	521,087	1,377,246	1,898,333	338,030	213,000	551,030	2,449,363
Professional fees	929,598	749,142	1,678,740	148,660	66,608	215,268	1,894,008
Training, conference, conventions, & meetings	74,869	583,658	658,527	6,268	57,523	63,791	722,318
Travel	73,090	209,117	282,207	6,154	22,296	28,450	310,657
Awards and grants	75,500	39,000	114,500	- 0 -	- 0 -	- O -	114,500
Occupancy	31,196	118,056	149,252	38,773	14,022	52,795	202,047
Insurance	2,492	9,432	11,924	2,167	2,052	4,219	16,143
Printing and publications	9,527	69,070	78,597	8,726	15,472	24,198	102,795
Telephone	8,690	26,846	35,536	13,566	3,941	17,507	53,043
Postage and shipping	32,275	78,167	110,442	3,817	17,556	21,373	131,815
Supplies	7,392	20,116	27,508	53,096	11,044	64,140	91,648
Rental and maintenance of equipment	10,491	39,703	50,194	13,039	4,716	17,755	67,949
Miscellaneous	38	98	136	16,588	5,704	22,292	22,428
Advertising	- O -	18,686	18,686	- 0 -	- 0 -	- O -	18,686
Dues and subscriptions	5,475	9,231	14,706	5,565	5,600	11,165	25,871
Depreciation and amortization	1,781,720 11,335	3,347,568 42,894	5,129,288 54,229	654,449 14,088	439,534 5,095	1,093,983 19,183	6,223,271 73,412
	\$1,793,055	\$3,390,462	\$5,183,517	\$668,537	\$444,629	\$1,113,166	\$6,296,683

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# 2014 IDF Walk for Primary Immunodeficiency Teams

**TEAM NAME** 

(Anti) Bodies in Motion A Couple of Walkers A Walk on the Wild Side Accredo Healthcare Advocate Munchkins Aidan's A-Team Aidan's Elwood Tigers Aidan's Herd Aislynn's Alicorns Alannah's Avengers

Alannah's Avengers All for Auntie Alyssa Andrew Olvera Archery Angels Autumn's Team B COSEY for Life Barb's Walkers

Baxter International Inc.

Baylee's Team
Bickerman Herd
Bihn 44
Bikers Afoot
Boston Strong
Boys for PI
Bradley's Team
Brandi's Zebra Zoo
Brayden's Zebra's Believe

Brockin' Zebras Burner Girl Zebras

Camden
Catch 'Em All
Chelsee's Herd
Christopher's Cadre
Chuck's Champs
Claire Leah

Claire's Dream Team

Coram CVS/Specialty Infusion Services

Corinthian Crusaders

Cortes

Courageous Zebras CSL Champion Cure for Hunter Curly Girl Club CVID Crushers Cynthia's CVID Gang David Center Walkers David's W.A.S Warriors

Dorian's Dream
Drennon
DWJ TEAM
Dylan's Explorers
Earning Our Stripes!

Ellie-Gators
Fancy IGG Y
Fire Station #2
Flad Fam Love
Flying Green Zebras
For The Love of Zebras
Friends of Freckles

Germinators Giving Back Go Joe 6

GoJoe - C ure G enetic D iseases

Good's Gang Grant Immunity Grant's Go Getters Gravell Girls

**Great Lakes Avengers** 

Grifols
Haemonetics
Hahesy
Halper's Helpers
Harper's Team
Hart & Sole
Hill Climbers
Hope For CWH

Houston, We Have a Problem

Huskies

Hypogamma Goblins I Believe In Miracles I Run for Seth

IgG America/US Bioservices/ASD Healthcare

In Memory of David Carey Incredible Jaiden: BE STRONG! Infusion Partners - Melbourne

Intouch Solutions Iris's Music Lovers Isa is a Fighter It's a Hard Walk Life

Ives Team
IVIG & Tonic
J&J's Amazing Zebras

Jaker's Bug Stompers Jenny's Family Jodi's Team Josie's Helping Hand Justin's Allstars JustKaela

KAREN'S ZEBRAS Karissa and Rylee Kate's Crusaders

Kathi B Katie Kats

J-Walkers

Kedrion Biopharma

Keeping up with Ali Kegan Redford King 'o the Cats Kristin's Krusaders Kyzier's Krew Lash Group

Laura's Amazing Antibodies

Laurie Austin

Les Zombies Aimables

LIFE

Life with Liam Lil Boy Crooks Lisa's Stripes Lisa's Team Long

Low Down Dirty Zebras Lurie's Children MacKenzie Maddie's Herd

Madeline and her Daddy Madi's (Ig)Gang Magnum PI Krew

Maish Family MakZebras

Mandy's Immune Platoon

MARS Inc. Mavericks

Maverick's Mission Megan's Immune Boosters

Melanna's Misfits Memories of Madelyn

MGH-PID

Mighty Mighty Mason Miles for Madison MJ's Team Naranjitos Niecy

Nip's Life Support No Big Diehl Norachu's Explorers North Dallas Zebras NYC Greyhounds Owens Super Kids Pet People for Pl Pivot Design Poretta & Orr, Inc. Prancercising Princesses

Princess Kennedy: Team Zebra IDF

Pumping For Pattiann

Purple Zebras Rare breed Rastad for PI RETC CADETS

# 2014 IDF Walk for Primary Immunodeficiency Teams cont.

**TEAM NAME** 

Rock Of Polacci Rock'n Ramundo's Rose Warriors

Ross/Rose Family for CVID

Run Reilly Ryan's Hope Ryan's Road Runners Ryder's Stripes Sarah's Journey Sassy Cygan steppers Savannah's Blue Devils

Schorn Storm SCID Angels See Jane Walk Shooting Stars Silver Wolf Hybrids SoCal Zebras

Soldiers for Agammaglobulinemia

SOLEO HEALTH Sonia Vohnout Spud's Superstars! Stacy Face Starcon Striders Stephen's Strollers Strides for Scaz Sub-Qutie Carter Guidry

Super Dawson SUPERBETH!

Superior Immune Globulins
Take the lead with Ethan and Reed!

Team Addie and Kenzie

Team Aidan
Team Belser
Team Betts
Team Biofusion
Team BioScrip
Team Boyders
Team BU
Team By-the-Sea
Team Caeden
Team Central Florida

Team CGD
Team Chee
Team CHOP
Team ClaudP
Team Cole
Team CuKo
Team Cure
Team Dr. T.
Team Fantastic
Team Frankie
Team Gabrielle

Team Gamma Girl Team Green Team Hammy Team Hampton Team Hoosiers Team Hope Team Hunter Team IDF

Team Inspiration
Team Jackson!
Team Jacob
Team Jared
Team Jeannemarie
Team Joel
Team Judy Koz!

Team Justin
Team Kathleen
Team Keel

Team Koopa's Troopas

Team Laura
Team Levi
Team Liam
Team Lisa
Team Marcia
Team Mason
Team Matthew - LIM
Team McComsey
Team MJ
Team Nate
Team Naughton

TEAM NOAH WE CARE ABOUT RARE

Team Olivia
Team Palmer
Team Pat
Team Penna
Team Pigott
Team Rath
Team Rhode Island
Team RMS FREEDOM60

Team Sam
Team Sebastian
Team Seth
Team Somara
Team Sophie
Team Stacia
Team Superman
Team Tara
Team Travis
Team Tuttle
Team Vickers
Team Vineyard
Team Wally
Team Waya

Team Whitney
Team Zeb!
Team Zebra
The Coat

The Duck Walkers!!!
The Elite Four
The Fighting Turtles
The Jirsa Fam
The Out-of-Towners
The Sub-Q-Tees

The Tortoise and the Zebras

The White Walkers

The Wonders (Team Vogel)

The Woodlands Associates of Jack & Jill

The Zack Pack The Zebrateers ToKaVi Tracy's Troops

Tremont Street Houligans

TRIGG Troop Ramus TXImmunoGoblins U Cant See Me Victorious Stripes

Wagner College Women's Lacrosse Walgreens Infusion Services

Walgreens warriors

Walk for Casey

Walk to a Different Hoofbeat

Walking for Ethan
We don't have a name yet

Welchlynn We're OK

West Coast Avengers West Side Stories

Westborough Rangers Football Team

Whooties
Wild Things
Wilson's Wonders

Xan
Zak Attack
Zebra Cats
Zebra Girls
Zebra Power
Zebra Strong
ZebraHeads
Zebras
Zebra's for K
Zebras in Tiaras

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Walgreens – IG Therapy Program

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