



# 2016 ANNUAL REPORT

A Year in Review



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**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. People with primary immunodeficiency diseases are the zebras of the medical world. So IDF says THINK ZEBRA!

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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.

# Broadening Our Reach

Because primary immunodeficiency diseases (PI) are rare, connecting 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.

## BROADENING OUR REACH

## IDF Retreats 2016

IDF Retreats are weekend gatherings for everyone in the PI community – patients, parents, siblings, partners and children. In 2016, we hosted 293 attendees in Boston, MA from June 17-19, which was the largest retreat ever, and 182 attendees gathered in Salt Lake City, UT from August 19-21. We had 26 states represented in Boston, with 41% first-time attendees at an IDF event, and there were 24 states represented in Salt Lake City, with 25% first-time attendees.

Retreats are a great way to discover the latest information and develop better approaches to living with PI – all while having a good time with a wonderful community. Special programs for individuals with Chronic Granulomatous Disease (CGD) and their families were offered, as well as sessions dedicated to young adults, including one in Boston for all young adults and another in Salt Lake for young adults with Severe Combined Immune Deficiency (SCID).



## IDF Education Meetings

Education is central to our mission, and each year IDF holds education meetings throughout the country. IDF has made a commitment to further enhance and increase the number of local 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 2016, IDF hosted 27 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 1,764 individuals. We had over 141 speakers volunteer to present at the meetings.

## IDF Outreach Initiative

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 IDF 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 Get Connected Groups

IDF Get Connected Groups are designed to connect individuals and family members living with PI in their local communities. The groups can occur at a local community room, library, coffee shop or other venues. They provide an opportunity for individuals to network and receive support in their local community. In 2016, each IDF Get Connected Group met 4-6 times on average in 16 different states. Through these meetings, IDF reached a total of 607 individuals.



## IDF Volunteer Network

The IDF Volunteer Network is committed to supporting the mission of IDF. This nationwide network of dedicated volunteers serves to advance the reach of IDF in areas of strategic importance to the PI community. In 2016, our network of volunteers created awareness by distributing thousands of education materials and spoke to approximately 2,827 people during 86 visits to plasma centers. IDF Peer Support Volunteers offered one-to-one encouragement to 236 individuals. Approximately 300 new volunteers registered in the IDF Volunteer Connection Center. 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 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 2016, IDF Teen Escape weekends were held in Northbrook, IL and Charlotte, NC with a total of 169 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 online. The IDF website offers an entire section devoted to teens that is filled with advice about living with PI as a teen, which can be found at [www.primaryimmune.org/teens](http://www.primaryimmune.org/teens). IDF provides multiple opportunities for teens to develop into strong, capable individuals.

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

**– Casey,  
IDF Teen Council Member**

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## IDF Young Adult Online Education Series

The IDF Young Adult Online Education Series was developed specifically to meet the needs and interests of this group. The program tackles the unique issues faced by young adults with PI (ages 18-34) all while connecting to others their age within the community. Presenters and participants alike asked and answered questions, discussed concerns, shared stories and connected with people who are living with the unique challenges that young adults with PI face. IDF has posted all webinar recordings on the IDF website to date. To listen to the webinar recordings, go to: <http://bit.ly/IDFWebinars>.

## 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.

## BROADENING OUR REACH

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 2016, 140 physicians utilized 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 2016, IDF sponsored four of these programs as part of our medical outreach.

## **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.

In 2016, members of the Clinical Immunology Society (CIS) and IDF joined forces to celebrate National Primary Immunodeficiency Awareness Month and World PI Week at the CIS Annual Meeting in April. At the meeting, renowned immunologists presented new research findings and discussed treatments for PI with more than 600 attendees. Throughout the conference, IDF distributed the Foundation's materials and resources. To show solidarity among those caring for and working on behalf of the PI community, IDF distributed PI Awareness t-shirts to all CIS Annual Meeting attendees, encouraging them to spread the word.

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 and #worldPIweek.

## **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.

# Advancing Research

Over the years, IDF has worked to help advance research of primary immunodeficiency diseases. 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.



## 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 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, where they can find out about some of the latest research and pose questions they have. Combining patient data with 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. It 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.

In 2016, the state-of-the-art platform held 3,068 health records and grew tremendously with 1,916 patients consented with USIDNET.

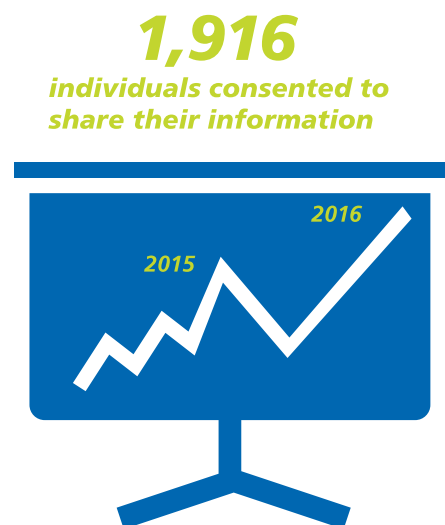
## IDF PI CONNECT Research Forum

IDF PI CONNECT currently has 1,916 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.

Patient discussions in the Forum are demonstrably driving research. Plans for an IDF research study examining body temperature and fever response are already underway and will be launched in winter 2018.

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.

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.

The cornerstone of this initiative is a registry of patient information, and the strength of this registry lies with individuals with PI. As of 2016, over 6,000 patients with PI have registered in the patient-consented 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.

### The following manuscripts were published using registry data:

- Leven EA, Maffucci P, Ochs HD, Scholl PR, Buckley RH, Fuleihan RL, Geha RS, Cunningham CK, Bonilla FA, Conley ME, Ferdman RM, Hernandez-Trujillo V, Puck JM, Sullivan K, Secord EA, Ramesh M, Cunningham-Rundles C. Hyper IgM Syndrome: a Report from the USIDNET Registry. *J Clin Immunol.* 2016 Jul;36(5):490-501.
- Perelygina L, Plotkin S, Russo P, Hautala T, Bonilla F, Ochs HD, Joshi A, Routes J, Patel K, Wehr C, Icenogle J, Sullivan KE. Rubella persistence in epidermal keratinocytes and granuloma M2 macrophages in patients with primary immunodeficiencies. *J Allergy Clin Immunol.* 2016 Nov;138(5):1436-1439.

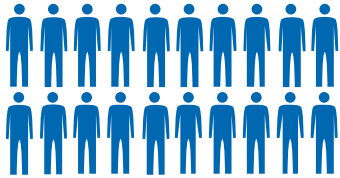
**6,000 Registered  
with USIDNET**



## IDF Survey Research

IDF surveys provide crucial insight into the personal impact of PI and helps 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 data collected by IDF helps fill this void.

The IDF Survey Research Center continues to provide timely data, analysis and expertise on issues of importance to the PI community. In 2016, 2,294 people with PI, the caregivers and healthcare professionals participated in five surveys developed by IDF.



**2,294 Patients and healthcare professionals participated in 5 IDF surveys**

### The IDF Survey Research Center played a major role in the following surveys:

- Consulted and managed participant recruitment for a Shire sponsored **Immunoglobulin Replacement Therapy Marketing Survey**.
- Consulted for the Primary Immune Deficiency Treatment Consortium (PIDTC) and the Clinical Immunology Society (CIS) for the development of the **Mental Health Concerns in Caregiver of Patients with PI Survey**.
- Partnered with PIDTC, SCID, Angels for Life Foundation, Wiskott-Aldrich Foundation and the Chronic Granulomatous Disease Association to develop and recruit for the **Non-Medical Care Survey for Patients with Primary Immunodeficiency Disease**.
- Survey development collaboration with CIS for the **Physician Health Insurance Survey**.
- Completed third and final Patient-Centered Outcome Research Institute (PCORI) milestone with the administration of the IDF 2016 Health Insurance Survey.

### IDF Survey Research Center also provided questionnaire development and data analysis expertise to other researchers and organizations:

- Consulted for PIDTC on the Wiskott-Aldrich Quality of Life Survey.
- Consulted for USIDNET on the CGD Survey.
- Continued support of IDF ePHR and IDF PI CONNECT.

### 2016 Publications:

#### ■ In-print:

- L Rider, N., Kutac, C., Hajjar, J., Scalchunes, C., Seeborg, F., Boyle, M., & Orange, J. Health-Related Quality of Life in Adult Patients with Common Variable Immunodeficiency Disorders and Impact of Treatment. (submitted August 2016, accepted May 2017). *Journal of Clinical Immunology*, 37, 461-475. doi: 10.1007/s10875-017-0404-8.
- 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.

#### ■ Submitted manuscripts:

- Immunologist Perspectives on Assessment and Management of Lung Disease in CVID: A Survey of the Membership of the Clinical Immunology Society and the European Society for Immunodeficiencies (ESID).
  - Over 300 Immunologists from CIS & ESID participated.
- IDF manuscript based on survey of pulmonologists has been submitted and is still in review.

## IDF Medical Advisory Committee and IDF Nurse Advisory Committee

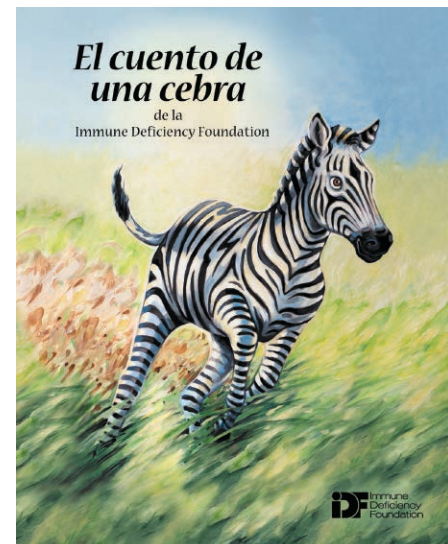
IDF has a Medical Advisory Committee (MAC) and Nurse Advisory Committee (NAC) comprised of prominent immunologists and clinicians dedicated to support the mission of IDF through the development of science-based standards and resources.

## 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 2016, there were two new publications introduced.

### *El Cuento de Una Cebra – A Zebra Tale from the Immune Deficiency Foundation in Spanish*

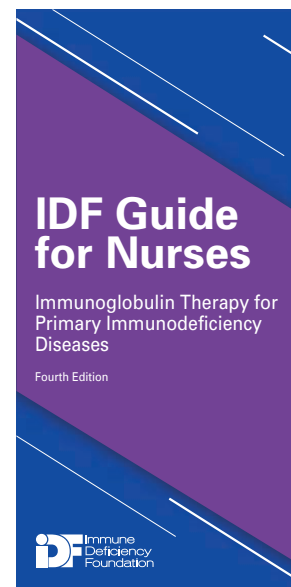
In 2016, IDF proudly published the *A Zebra Tale* from the Immune Deficiency Foundation in Spanish. This illustrated storybook written for children—young and old—living with PI and their families provides hope and encouragement. *A Zebra Tale* chronicles the journey of a young horse who faces recurrent 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 Guide for Nurses Immunoglobulin Therapy for Primary Immunodeficiency Diseases – Fourth Edition*

In 2016, IDF published the fourth edition of the *IDF Guide for Nurses Immunoglobulin Therapy for Primary Immunodeficiency Diseases*. Developed by the IDF Nurse Advisory Committee, the guide includes general information about PI diseases, delivery of immunoglobulin (Ig) replacement therapy, product selection and characteristics, troubleshooting intravenous and subcutaneous Ig therapy, and more.

This new edition includes changes in dosing and delivery as well as additional instructions for teaching patients. The sleek design and pocket size make it easy to use for busy nurses. This popular guide provides direction for nurses to administer Ig replacement therapy in the safest and most effective way.



# Dedicated to Future Generations

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 fourth 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 2016, IDF's patient advocacy services helped fill the need for over 7,883 requests from individuals and families seeking education, information and assistance, which is 862 more than 2015. IDF has answers and information when patients and families need it—online or by phone. That is the power and the dependability of IDF.

## 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 2016, there were more than 418 calls regarding insurance. In 2016, 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 they're feeling. 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 a personal experience on living with PI. In 2016, 236 individuals requested peer support.

## IDF Friends – The Community Page

IDF Friends is a discussion forum 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 on living with PI. It continues to attract an average of 75 new users each month, and in total, the 5,780 members on the site have posted over 41,500 times on 4,816 topics.



DEDICATED TO FUTURE GENERATIONS

## 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.

*In 2016, over 4,000 walkers from 438 teams in 14 cities helped raise more than \$440,000*

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 as of 2016 have raised over \$2 million since the first walk in 2013.

In 2016, over 4,000 walkers from 438 teams in 14 cities helped raise more than \$440,000 for IDF Walk for PI and when sponsor raised funds are included, more than \$1.1 million was raised. National walks were held in Atlanta, Boston, Charlotte, Chicago, Cleveland, Fort Lauderdale, Houston, Los Angeles, Minneapolis, New York City, Philadelphia, St. Louis and the Nationwide Virtual Walk.

In 2016, we had 2 IDF Community Walks held in Blountville, TN and Omaha, NE. IDF Community Walks are 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.

The IDF Order of the Zebra 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 2016, IDF had 82 members raise over \$1,000 each and become a part of the exclusive Order.



## Public Policy

Through advocacy efforts, IDF lays the groundwork for the promise of an easier tomorrow for those living with PI. By mobilizing individuals, families and healthcare providers throughout the country, IDF continues to be at the forefront of issues relevant to this community. Public policy issues that are critical to patients at the national and state levels are monitored and addressed through the IDF Advocacy Center on the IDF website. Additionally, 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 specialist's 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 2016

The annual IDF Advocacy Day on Capitol Hill, held April 21, 2016, focused on garnering legislative support for opposition against the Centers for Medicare and Medicaid (CMS) proposed rule containing a payment demonstration that would severely reduce reimbursement for Part B drugs and its potentially devastating impact on access to medical care for the PI community. IDF continued its goal of gaining Congressional support for HR 1600, the Patients' Access to Treatments Act.

Targeting Members of the Senate HELP Committee and Members of the House Energy and Commerce Committee, IDF put special emphasis on inviting volunteers who had not previously participated in an Advocacy Day event in order to grow the base of trained grassroots advocates. Over 65% of attendees were first-time participants, and 70 patients (55 adult advocates and 15 young adults) participated, representing 40 states. It was a productive day with nearly 160 Congressional meetings resulting in several legislative letters sent to CMS and a hearing in front of the Energy and Commerce Committee.

### Medicare IVIG Access Demonstration Project

After seven years of intensive advocacy efforts, the Medicare IVIG Access Act was passed by Congress in December 2012 and signed into law by the President in January 2013. The law established a demonstration project that allows Medicare to pay for immunoglobulin (Ig) therapy plus items and services for Medicare beneficiaries to receive intravenous immunoglobulin (IVIG) in the home. Over 1,700 people are participating in the program. The project is set to end September 30, 2017 and enter its evaluation phase, and it is anticipated that the project will provide the data necessary to make home infusion a permanent benefit for patients with PI. While the evaluation is taking place, IDF advocates for the project to continue to treat beneficiaries until either allocated funds are spent or the evaluation is completed and a decision is made to make or not make IVIG in the home a permanent benefit. Throughout 2016, IDF developed significant bi-partisan support for the extension of the demonstration project. [Representatives Brady (R-TX) and Matsui (D-CA) introduced legislation in 2017 to extend the demonstration project subject to already allocated funds for the project to December 31, 2020. That bill passed by both Houses of Congress and was signed by the President, extending the project, with no gaps in coverage for those enrolled in the Demonstration.]

### Accelerate the Start of the Medicare SCIG Home Infusion Benefit

In December 2016, Congress passed the 21st Century Cures Act (Cures) which, while increasing funding for important research, unfortunately included revised reimbursement provisions that now threaten access to treatment for people with PI on Medicare who receive subcutaneous immunoglobulin (SCIG) therapy. To "pay for" the provisions of the Cures Act, effective January 1, 2017, Congress significantly reduced reimbursement for the cost of drugs, including Ig. As a result of this reduction, some providers have stopped providing services, some refuse to take new Medicare beneficiaries and some are waiting to see if Congress will fix this problem.



IDF worked diligently to get language in Cures that would authorize Medicare to develop reimbursement categories to pay for the services needed to train and monitor people who receive SCIG. While the language recommended by IDF was included in the legislation, its start date is January 1, 2021, a four-year delay from when the payment reductions began. IDF worked with legislators in 2017 to introduce legislation to move the start date to 2018 for the new services reimbursement for training and monitoring of Medicare beneficiaries who receive SCIG, closing the treatment gap. (The bill passed the House in 2017 and awaits action in the Senate, which is expected by the end of 2017.)

### **Cadillac Tax**

IDF is monitoring the 40% excise tax on high priced employer-sponsored health insurance plans, also known as the “Cadillac Tax,” that was scheduled to begin in 2018 but has been delayed by Congress to 2020. IDF has been proactive in raising awareness on the issue by joining the Alliance to Fight the 40 coalition and serves on the Alliance’s steering committee. This tax will affect far more than just luxury plans and have a devastating impact on those with severe chronic diseases, such as individuals with PI.

### **Biosimilars**

Since the passage of the Affordable Care Act (ACA), IDF has expressed concerns regarding patient safety aspects of the pathway for biosimilar products. IDF took the lead in forming the patient only coalition of Patients for Biologics Safety and Access (PBSA) with 23 other organizations on unique naming issues, patient safety concerns and the necessary requirements for any biosimilar pathway to be successful and safe for people with PI.

### **Affordable Care Act (ACA) Implementation**

With the election of a Republican administration in 2016 and Republican control of both houses of Congress, attempts were and still are being made to “Repeal and Replace” the Affordable Care Act (ACA). IDF and patient groups nationwide began advocating in 2016 to keep all of the current patient protections of the ACA including guaranteed issue for all people with pre-existing conditions, a ban on annual and lifetime coverage caps, retention of annual out-of-pocket cost caps and need for non-discriminatory health plans. (In 2017 the ACA remained unchanged).

### **Blood Safety**

In 2016, IDF continued its leadership of the American Plasma Users Coalition (A-PLUS), a group of patient organizations serving patients treated with products derived from blood plasma. A-PLUS has emerged as a means of communicating joint positions on federal issues including the submission of comments to federal agencies and Congress on Third Party Payment of Qualified Health Plan Premiums, Notice of Benefit and Payment Parameters for 2017, and the Part B Drug Payment Model. Additionally, A-PLUS sent letters in support of Nebraska legislation changing the age of plasma donation to 18 years old and sent a joint letter with PLUS of Europe in support of compensated plasma donations in Canada.

### **Health Access Advocates**

Starting in 2016, IDF’s public policy and volunteer development staff worked to create a robust Health Access Advocate (HAA) Program as an enhancement to its public policy volunteer efforts. This program ensures that there are volunteer advocates from across the country who can work within their local and state communities to enhance access and remove barriers to care for the PI community.

HAA’s are prepared to contact local legislators on behalf of IDF, testify at legislative hearings, work with other patient organizations and stakeholders on state and federal issues, mobilize other members of the PI community and participate in various activities that further IDF’s mission. Efforts in 2016 included the launch of a new training process for this volunteer role consisting of a new application, guide and training video, as well as recruitment of potential advocates and the screening and selection of participants. Also, IDF has held trainings and identified specific advocacy issues for volunteers to address throughout the year. This has resulted in a network of well-trained HAA’s that are adequately prepared to perform the tasks asked of them.

## Public Policy *continued*

### State Advocacy

IDF works with other like-minded patient organizations supporting state legislation that stops the use of increased cost sharing through specialty tier co-insurance practices. To this end, IDF established Affordable Co-pays and Treatments (ACT) for Nevada in 2016, to address the issue of discriminatory health insurance practices in Nevada in which people with PI and other chronic illnesses have are being singled out and forced to pay unfair portions of healthcare costs – and are potentially being driven out of their current plans. Throughout 2016, IDF coordinated a coalition of ten patient organizations active in Nevada to support these policy change efforts. IDF worked with these partner organizations to craft proposed legislation that would ensure Nevadans have options when selecting a health plan by requiring insurers to have at least 25 percent of the plans they offer at each coverage level provide a flat dollar co-pay option for all prescription medications.

In addition, IDF has been active in five other state access to care coalitions (IL, MD, PA, NJ and OH) that have proposed legislation to address barriers to medication access. Efforts have included, sending action alerts, writing testimony, meeting with legislative leadership (NJ), presenting oral testimony (PA) and participating in workgroups (MD).

### SCID Newborn Screening

In 2016, IDF continued actively campaigning for all 50 states to add Severe Combined Immune Deficiency (SCID) to their newborn screening panels following the May 2010 decision by the U.S. Department of Health & Human Services (HHS) to include SCID as a core condition on the Recommended Universal Screening Panel.

Twelve new states began screening in 2016: Alaska, Georgia, Idaho, Kentucky, Maryland, Montana, New Mexico, North Dakota, Pennsylvania, Puerto Rico, Tennessee and Vermont, bringing the total number of states conducting SCID newborn screening at the end of 2016 to 42. [An additional three states (Arizona, Missouri and North Carolina) have begun screening for SCID in 2017.]

Additionally, in 2016, IDF developed and is now distributing a Spanish language translation of IDF SCID education materials for parents. IDF also developed a video for families of babies who have received a diagnosis of SCID through a grant from the American Public Health Labs (APHL). This video will be distributed by each state as part of its follow-up protocol, following a diagnosis. Also, IDF began developing a brochure for families of babies who, through SCID newborn screening, are found to have low T cells. The brochure provides information and recommendations for children who do not have SCID but should be followed because of their low T cell levels.

### Private Insurance

In recent years, IDF has been aggressive and persistent with advocacy efforts to help patients, their families and clinicians navigate their way through the maze of access issues that are unique to PI, such as appropriate Ig guidelines and standards of care, sites of care and access to specialists. Reaching out and educating insurance payers and healthcare professionals about the need for open access and the unique needs of our patients will result in better care. This campaign has resulted in publication of several articles and op-eds in payer industry publications as well as draft model Ig therapy guidelines that can be proffered to payers. IDF continues to advocate and effectively intervene on behalf of patients with PI to get insurance policy guidelines changed to ensure patients have access to the therapies and services that they need.

With the increased emphasis by payers on Values Health Care (VHC), organizations like the Institute for Clinical and Economic Review (ICER), have emerged. These organizations support best patient outcomes in theory but often support policies focused on reduced costs. With these developments in the healthcare system and the expected changes in the ACA, patient advocacy organizations like IDF are more important than ever to carry the patient voice into these new processes.

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# 2016 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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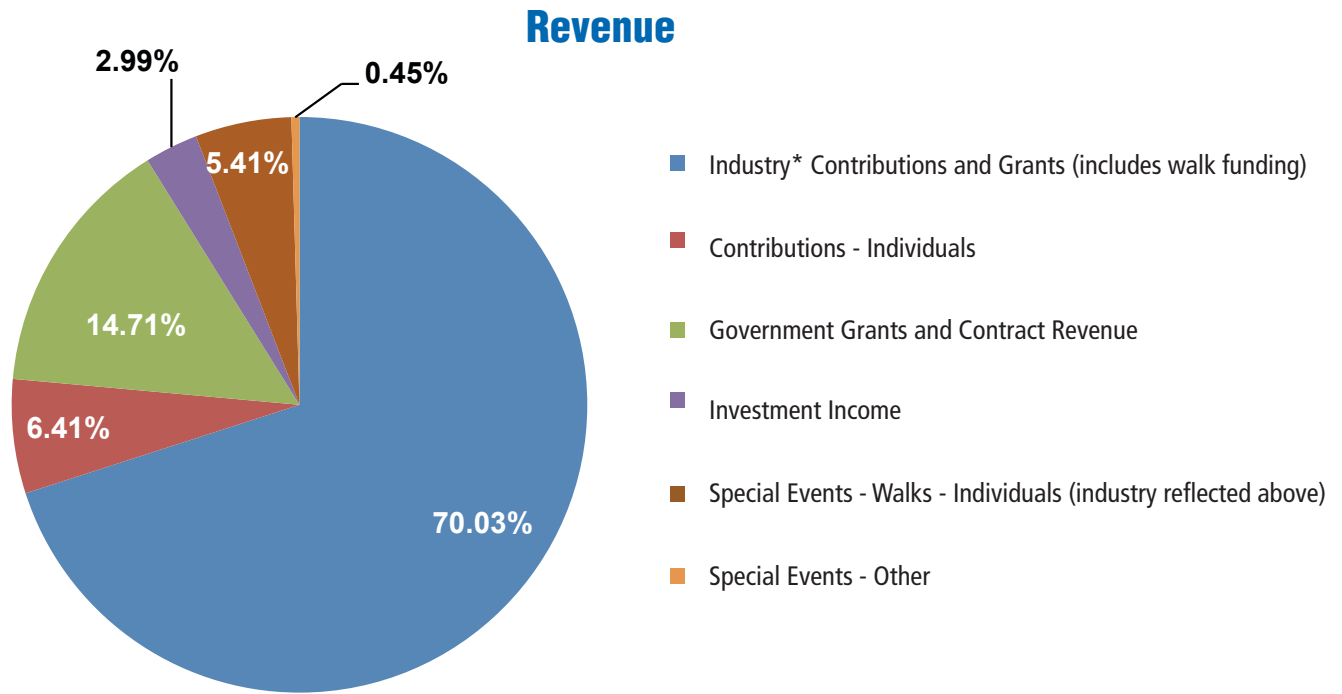
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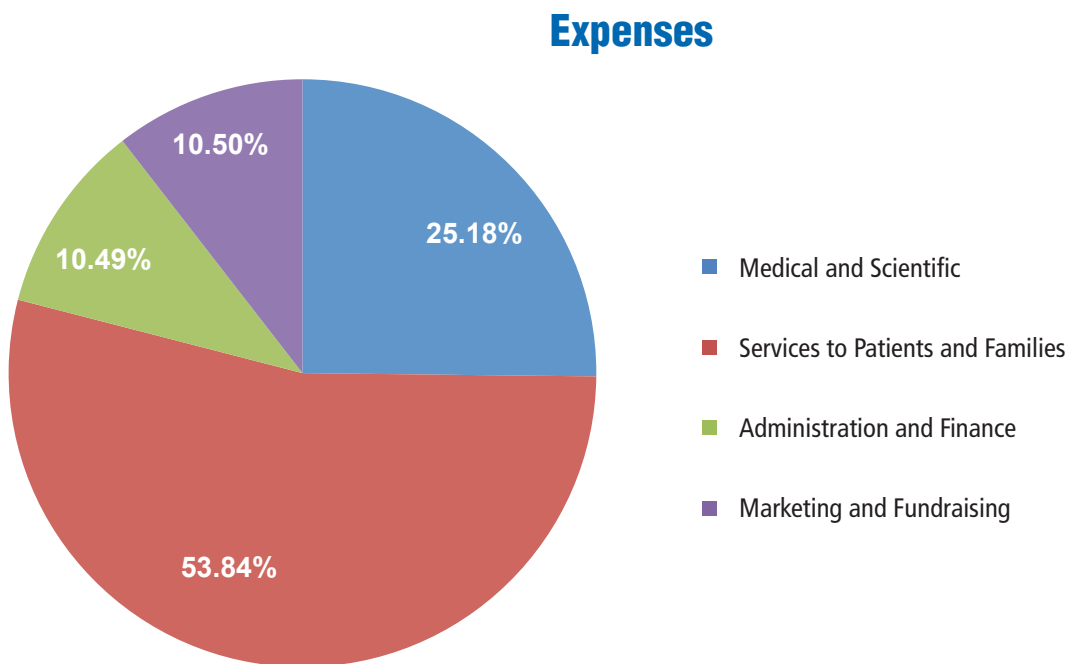
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Accredo Healthcare  
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# 2016 Revenue



\*This includes contributions for our programs, patient education and events from pharmaceutical, biotechnology and medical device companies.



# Statement of Activities & Changes

## in Net Assets for the Year Ending December 3, 2016

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
<b>PUBLIC SUPPORT AND REVENUE:</b>				
Public support:				
Contributions and grants	\$ 4,301,474	\$ 1,769,404	\$ - 0 -	\$ 6,070,878
Net assets released from restrictions	1,375,566	(1,375,566)	- 0 -	- 0 -
Total public support	<u>5,677,040</u>	<u>393,838</u>	<u>- 0 -</u>	<u>6,070,878</u>
Government grants and other contract revenue	<u>1,204,053</u>	<u>- 0 -</u>	<u>- 0 -</u>	<u>1,204,053</u>
Revenue:				
Investment income	244,991	- 0 -	- 0 -	244,991
Other income	60,730	- 0 -	- 0 -	60,730
Special events	603,301	- 0 -	- 0 -	603,301
Total revenue	<u>909,022</u>	<u>- 0 -</u>	<u>- 0 -</u>	<u>909,022</u>
Total Public Support and Revenue	<u>7,790,115</u>	<u>393,838</u>	<u>- 0 -</u>	<u>8,183,953</u>
<b>EXPENSES:</b>				
Program services:				
Medical and scientific	1,838,427	- 0 -	- 0 -	1,838,427
Services to patients and families	3,931,214	- 0 -	- 0 -	3,931,214
	<u>5,769,641</u>	<u>- 0 -</u>	<u>- 0 -</u>	<u>5,769,641</u>
Supporting services:				
Administration and finance	765,611	- 0 -	- 0 -	765,611
Marketing and fundraising	766,301	- 0 -	- 0 -	766,301
	<u>1,531,912</u>	<u>- 0 -</u>	<u>- 0 -</u>	<u>1,531,912</u>
Total Expenses	<u>7,301,553</u>	<u>- 0 -</u>	<u>- 0 -</u>	<u>7,301,553</u>
CHANGE IN NET ASSETS	488,562	393,838	- 0 -	882,400
NET ASSETS, BEGINNING OF YEAR	<u>6,756,379</u>	<u>1,421,216</u>	<u>- 0 -</u>	<u>8,177,595</u>
NET ASSETS, END OF YEAR	<u>\$ 7,244,941</u>	<u>\$ 1,815,054</u>	<u>\$ - 0 -</u>	<u>\$ 9,059,995</u>



# Statement of Functional Expenses

for the Year Ending December 31, 2016

	PROGRAM SERVICES			SUPPORTING SERVICES			Grand Total
	Medical and Scientific	Services to Patients and Families	Total	Administration and Finance	Marketing and Fundraising	Total	
Salaries	\$ 572,622	\$ 1,401,984	\$ 1,974,606	\$ 384,443	\$ 293,411	\$ 677,854	\$ 2,652,460
Employee benefits	66,001	130,807	196,808	56,726	29,678	86,404	283,212
Payroll taxes, etc.	45,527	109,899	155,426	25,568	23,938	49,506	204,932
	684,150	1,642,690	2,326,840	466,737	347,027	813,764	3,140,604
Professional fees	734,455	794,562	1,529,017	117,282	70,142	187,424	1,716,441
Training, conference, conventions, & meetings	82,253	475,492	557,745	782	156,927	157,709	715,454
Travel	94,694	292,904	387,598	3,512	31,813	35,325	422,923
Awards and grants	77,706	42,243	119,949	10,000	- 0 -	10,000	129,949
Occupancy	55,524	111,399	166,923	82,249	22,486	104,735	271,658
Insurance	10,633	9,233	19,866	6,881	2,483	9,364	29,230
Printing and publications	17,354	168,369	185,723	7,799	22,460	30,259	215,982
Telephone	13,558	28,201	41,759	16,628	5,046	21,674	63,433
Postage and shipping	8,487	110,270	118,757	6,834	37,933	44,767	163,524
Supplies	20,894	37,578	58,472	16,908	9,233	26,141	84,613
Rental and maintenance of equipment	12,303	45,593	57,896	14,384	4,400	18,784	76,680
Miscellaneous	- 0 -	- 0 -	- 0 -	1,550	7,481	9,031	9,031
Advertising	7,203	135,138	142,341	- 0 -	24,480	24,480	166,821
Dues and subscriptions	9,376	17,806	27,182	6,081	20,406	26,487	53,669
	1,828,590	3,911,478	5,740,068	757,627	762,317	1,519,944	7,260,012
Depreciation and amortization	9,837	19,736	29,573	7,984	3,984	11,968	41,541
	<u>\$ 1,838,427</u>	<u>\$ 3,931,214</u>	<u>\$ 5,769,641</u>	<u>\$ 765,611</u>	<u>\$ 766,301</u>	<u>\$ 1,531,912</u>	<u>\$ 7,301,553</u>

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# IDF Walk for Primary Immunodeficiency Teams 2016

## TEAM NAME

#GioStrong	Clan Maish	Infusion Sweets	Magis
#teamHailey	Courageous Zebras	Intactivists	Magnum PI Krew
#teamrachpach	CSL Behring	Intouch Solutions	Makenna's Minions
#walkin'tallforPI	CSL Plasma	Irish Zebras	Making Strides for PI
AAIR of Charlotte	Cynthia's CVID Gang 2016	Isa is a Fighter	Maldonado Marvels
Abbie's Herd	Dahlia Lovers	Isabella's Immunogladiators	Mandy's Immune Platoon
AbsoluteCARE	Dancing Zebras	It's an Ashley Thing	Maranda
Accredo Health Group	Dare to Walk	Jack and Jill Associates, The Woodlands Texas	Marchesano4IDF
ADMA Bio Centers	David's W.A.S. Warriors	Jacob's Ninja Turtles	Mark the Shark
AJ's Platoon	DeKalb Biolife Plasma Services	JDCH Division of Allergy and Immunology	Maryland Mighty
Aj's Team	Delilah's Crew	Jenny's Journey	Maverick's Mission
Alanna's Dazzle	Desirea's Zebras Team	Jerry's Test	McPhee
Albert's Angels	Downtowners	Jessica's Jamboree	Megan's Herd
Alek and Kael's Dream Team	Drew & Mary Strength in Numbers	Jillsy	Michelle
Ally's Wish	Elijah's Warriors	Jodi's Team	Michelle's Family of Zebras!
Amery's Army	Erin's Antibodies	Jonah's Flyers	Mighty Mighty Mason
Amy's Zebra Angels	FHS SADD	Judy's Jammers	Mighty Mo's Musketeers
Anna's Angels	Fontenot Zebras	Kaeser's Krew	Mikie G
April's Amigos	Frankie's Friends	Kailey's Superhero Team	Minions
Ashlee's Striped Sisters	Frear Family For Primary Immune Deficiency	Kari's Crusaders	Miracle Walker
Ashley's Zebra Stripes	Gabby's Team	Katlyn's Klan	Misfits
Atlanta Allergy & Asthma	Gabriel's Angels	Kaylee's Courage	Momma Dukes
Atlanta South Zebras	Gatesville Zebras	Kaylyn's team	Nana's Network
Avery's Zebras	Gifford's Fightin Zebras	KDWHEAT's	Nancy's Walkers
Awesome Dawson	Glennon Zebras	Kedrion Team	Nell & Jerome
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Bad Blood	Green Zebras	Keeping Up With Kate	NKT
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Britt's PI Awareness Squad	Heidi's Heros	Lois's Coming back Love	PromptCare Home Infusion
Britt's Trapezoids	Hilton Americas- Houston	Love Wins	Rachel Rocks CVID
Brockin' Zebras	Holly's Friends & Family	Lucas's Stars	Rashann's Stampede
Caiden's Crew	Horizon Pharma Team CGD	Luke's Crew	Rayden Raiders
Caleb's Crusaders	Hot shots	Luke's Zany Zebras	Reisman Rocks
Carolina Zebra's	Houston THINK Zebra!	Lurie Childrens	Rheana's Roadies
Chelsee's Herd	IGA Warriors	Mac's Pack	Rhodes of Hope
Christian's Wolf Pack	IgG America	Maddie's Herd	River's Hope
Christina's Crew	Incredible Zebras	Madi's Zebras	RMS Freedom for Living
Chuck's Champs			RNH Army of Awesomeness

Samantha's Herd	Team Dana	Team Rossi	The Zebrateers
Sarah's Journey	Team Dean	Team Sam	The Zeebs
Together We Can Beat PI	Team DISCOvery	Team Saul	Thundering Hooves
Schwarz Force	Team DWJ	Team Sean	Tommys Troop
Sean Deal	Team Elise	Team Seth	Tracy's Troops
See Jane Walk	Team Elizabeth	Team Sierra Jo Fields	Trixie
Seymour Zebras	Team Emmett	Team Slack	Troop Ramus
Smith Zebras	Team Friars	Team STC	Tschida's for Zebras
SmolaStars	Team Gamma Girl	Team StuPlfy	Turner Power
Soleo Health	Team Ganas	Team Superman	TZ's Herd
Southern Zebras	Team Gee	Team Tara	University Hospitals Allergy / Immunology
Spiece Immunity	Team Ginger	Team Taylor	Up and at 'em!
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Team All That Jazz	Team Mass General Hospital	The Low Down on PIDDs	Zebra Wings
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Team Baylee	Team Naughton	The Mouse's Team	ZEBRA: Zany Eclectic Beings Rapidly Ambulating
Team Becki	Team Naveyah	The O'Rourkes	Zebra's For BioRX
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