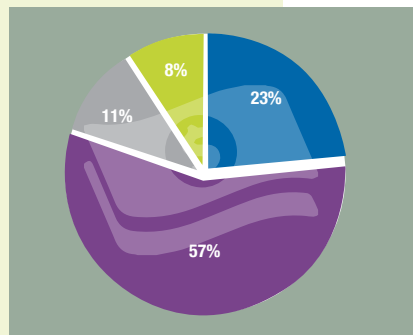


2017 ANNUAL REPORT

a year in transition





2017 ANNUAL REPORT

a year in transition

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

Following more than 37 years of skilled and passionate leadership, IDF Founder Marcia Boyle retired as President in August 2017. After a nationwide search, John G. Boyle was selected by the Board of Trustees to lead IDF as President & CEO.

Building programs where people living with PI can connect with other patients, families and healthcare professionals has remained critical. We worked to sustain initiatives that foster relationships within the community and that provide the community with the information and resources they richly deserve.

We helped advance research and worked collaboratively with expert clinicians from across the country, because our major focus is to better understand patient experiences and improve outcomes.

Individuals and 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.

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.

2017 ANNUAL REPORT



EDUCATION

Education is central to our mission, and each year IDF holds informative gatherings 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.

- **IDF Educational Presentations.** 17,066 patients and healthcare professionals reached with 230 presentations in 115 cities, 41 states and 2 countries
- **IDF Education Meetings.** 89 healthcare professionals volunteered at 35 education meetings attended by 1,250 individuals.
- **382,250 education materials** distributed at no cost to patients and families.



WORKING TOGETHER

Volunteers are the heart of what we do.

- **IDF Get Connected Groups.** 28 Get Connected Leaders of 26 Get Connected Groups in 17 states coordinated 68 get-togethers attended by 614 individuals. These groups are designed to connect individuals and family members living with PI in their local communities.
- **IDF Peer Support Program.** 179 individuals offered one-to-one support. This program connects people and patients who share similar relationships to PI. Participation 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.
- **IDF Plasma Partner Program.** Plasma partner volunteers made 81 visits to plasma centers, where they shared their stories with donors, adding a face and humanizing the experience of plasma donation.
- **IDF Volunteer Network.** We welcomed 224 new volunteers. This nationwide network of dedicated volunteers serves to advance the reach of IDF in areas of strategic importance of the PI community.



UNITING THE COMMUNITY

We strive to connect families together with not only each other but healthcare professionals as well.

- **IDF 2017 National Conference.** The 2017 National Conference was held in Anaheim, CA from June 15-17. 1,276 individuals attended, with 556 being first-time attendees and 436 being first-time IDF event attendees. 153 individuals attended the youth program. Collectively, there were individuals from 43 states and 11 countries who came to attend 63 sessions presented by 66 presenters and 39 scholars. The IDF National Conference is our preeminent event, held biennially in varied and diverse locations throughout the country, and is a platform for all facets of the PI community. From physicians to nurses to specialized life management experts, patients and families are presented with an unsurpassed opportunity to network with those on the cutting edge of research and treatment. It brings together all sectors of the PI community, and is the world's largest gathering of families living with PI.
- **IDF Walk for Primary Immunodeficiency.** In 2017, 3,600 walkers from 16 cities and 397 teams came together and raised more than \$940,000 for IDF Walk for PI. IDF Walk for PI unites the PI community to help create better lives and find cures for individuals living with these rare, chronic diseases. IDF Walk for PI is our largest fundraising event, and funds IDF research grants awarded for patient-focused research in the field of PI. Patients, along with their families and friends, come together to walk for PI, and raise awareness and funds.
- **IDF Teen Escape.** IDF Teen Escapes 2017 were held in Dallas, TX (July 15-16, 2017 with 102 attendees, including 34 teens and 50 parents) and West Harrison, NY (July 29-30, 2017 with 96 attendees, including 34 teens and 43 parents). At the IDF Teen Escape, teens, aged 12-18, have a chance to meet face-to-face for a long weekend and learn from healthcare and life management experts. Issues they face are tackled while confidence is gained. Meanwhile, parents participate in sessions geared toward their own issues and concerns.

382,250
education
materials
distributed at
no cost

224
new
volunteers

1,276
attendees at
IDF 2017
National
Conference

3,600
walkers
across
16 cities



STREAMLINING THE ONLINE USER EXPERIENCE

Enhancing our website.

- **IDF My Account.** Creating an account through IDF My Account allows users to customize how they would like to stay connected with IDF. It gives users access to IDF resources and materials, and lets them update their mailing preferences so they're always hearing exactly what they want to hear.
- **New website design.** 900,000+ users accessed primaryimmune.org. We recognized there were new and emerging needs with our community and our previous website needed to be optimized. The new design offers a more streamlined and intuitive experience for the user.



ADVANCING RESEARCH

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 PI CONNECT and IDF ePHR.** In 2017, there were 3,361 IDF ePHR health records with 2,209 IDF PI CONNECT participants. IDF PI CONNECT empowers patients to participate and help transform research by consenting to share their data and their individual experiences. Individuals become a part of IDF PI CONNECT through IDF ePHR, our electronic personal health record, providing users with the latest advancements in health record system management.
- **United State Immunodeficiency Network (USIDNET).** 6,584 registered participants in USIDNET. USIDNET was established to advance scientific research of 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.
- **IDF Survey Research.** 5,557 people and healthcare professionals participated in 5 major, patient-focused IDF surveys. Surveys provide crucial insight into the personal impact of PI and help IDF develop initiatives for improved diagnosis and treatment.



MEDICAL OUTREACH

IDF actively promotes and develops medical education and resources to improve the diagnosis, treatment and care of PI.

- **LeBien Visiting Professor Program:** In 2017, there were 9 programs which promoted improved medical knowledge by offering teaching hospitals the services of a leading clinical immunologist to lead Grand Rounds and other educational activities to their healthcare providers.
- **Consulting Immunologist Program:** In 2017, 98 physicians utilized our Consulting Immunologist Program which provided physicians the opportunity to consult with expert clinical immunologists about patient-specific questions and obtain valuable diagnostic, treatment and disease management information.



COMMUNICATIONS

Connecting through hashtags and beyond.

- **IDF Publications.** Heralded as the best patient resources for PI in the world, IDF publications are developed by world renowned immunologists and healthcare professionals. Two new publications were published in 2017. The *Immune Deficiency Foundation Transition Guide: Pediatric to Adult Care*, which examines the transition from pediatric to adult healthcare, helping young people with their PI prepare to make healthcare decisions and manage their healthcare on their own. And *Understanding Low T Cell Results from Your Baby's Newborn Screening: A Guide from the Immune Deficiency Foundation*, which helps families understand what their baby's low t cell results mean and why an evaluation follow up with a specialist is important.
- **National Primary Immunodeficiency Awareness Month (April) and World PI Week (April 22-29).** 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.
- **IDF and TZ Social Media Stats.** At the end of 2017, we had 5,461 Facebook likes; 2,128 Twitter followers; 2,128 Instagram followers; and 5,460 users on IDF Friends. TZ, the IDF Zebra had 324 Twitter followers and 365 Instagram followers.
- **IDF Resource Center.** IDF videos have been viewed more than 94,542 times with 22 new videos created and nearly 2,000 resource articles.
- **Newsletter and E-newsletter.** 50,000 individuals received the IDF newsletter, *IDF ADVOCATE*. 25,000 individuals received the monthly e-newsletter, Primary Immune Tribune.



PUBLIC POLICY

The voice of the PI community.

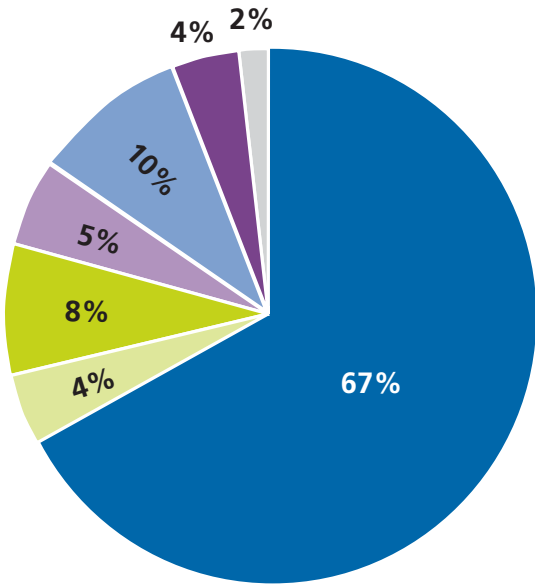
- **Advocacy Day 2017.** In 2017, 49 patients and family members participated in 80 legislative meetings. The annual IDF Advocacy Day on Capitol Hill focuses on garnering legislative support for the PI community. Members of the community met face-to-face with legislators and sat in on Congressional meetings.
- **IDF Action Alerts.** 8,400 letters and calls were made to policymakers as a result of IDF Action Alerts. This system is a tool utilized to mobilize our community by promoting our activists to take immediate action on legislative issues relation to PI.
- **SCID Newborn Screening Campaign.** Much progress was made in 2017 to ensure all babies born in the U.S. are screened for Severe Combined Immunodeficiency (SCID), one of the most severe forms of PI. At the time of this publication, all states in the U.S. are now screening for SCID, effective December 10, 2018 with the addition of Louisiana. IDF will continue to actively support and educate families affected by SCID.

2017 ANNUAL REPORT

REVENUE FOR THE YEAR ENDING DECEMBER 31, 2017

Industry* Contributions and Grants (includes walk funding)	\$6,229,353	67%
Contributions - Individuals	408,415	4%
Government Grants	744,245	8%
Contract Revenue	496,189	5%
Investment Income	888,860	10%
Special Events - Walks - Individuals (industry reflected above)	379,603	4%
Special Events - Other	168,636	2%
Total	\$9,315,301	100.00%

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

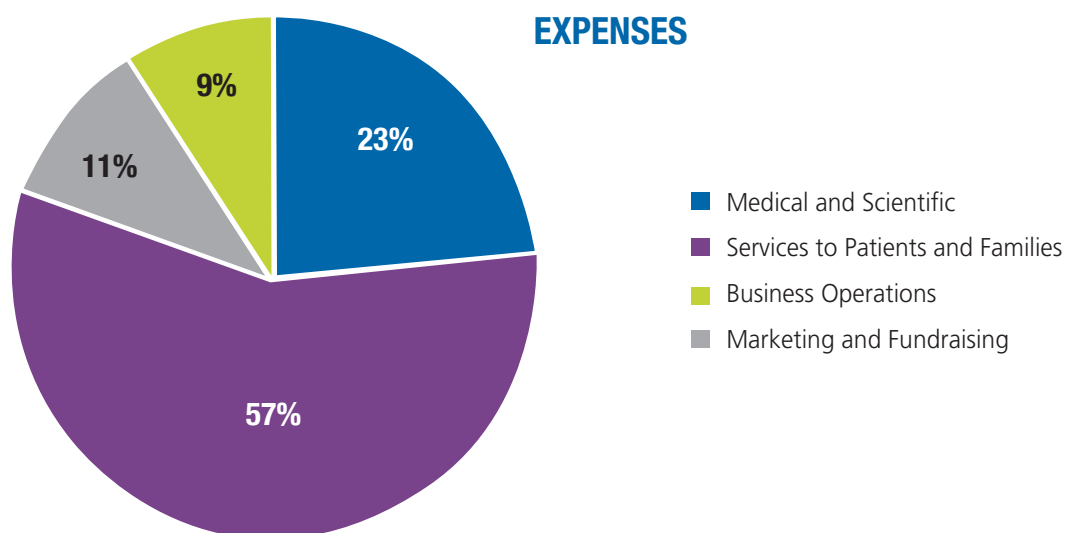


REVENUE

- Industry* Contributions and Grants (includes walk funding)
- Contributions - Individuals
- Government Grants
- Contract Revenue
- Investment Income
- Special Event - Walks - Individuals (industry reflected above)
- Special Events - Other

STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDING DECEMBER 31, 2017

	PROGRAM SERVICES		SUPPORTING SERVICES		Total
	Medical and Scientific	Services to Patients and Families	Business Operations	Marketing and Fundraising	
Salaries	\$627,856	\$1,387,412	\$396,786	\$297,549	\$2,709,603
Employee benefits	82,721	139,255	81,741	28,268	331,985
Payroll taxes, etc.	49,332	111,658	28,891	25,374	215,255
	759,909	1,638,325	507,418	351,191	3,256,843
Professional fees	632,287	1,081,023	256,547	54,119	2,023,976
Training, conference, conventions, & meetings	67,708	1,304,508	2,197	192,103	1,566,516
Travel	83,115	263,899	13,935	27,551	388,500
Awards and grants	286,679	3,500	- 0 -	- 0 -	290,179
Occupancy	57,009	139,063	82,854	25,360	304,286
Insurance	15,247	9,971	12,255	2,441	39,914
Printing and publications	40,156	183,021	4,455	42,444	270,076
Telephone	10,856	21,000	7,922	3,545	43,323
Postage and shipping	37,021	111,630	5,146	29,553	183,350
Supplies	22,708	71,584	13,635	8,407	116,334
Rental and maintenance of equipment	15,832	37,137	24,280	3,736	80,985
Miscellaneous	12,400	- 0 -	2,706	11,049	26,155
Advertising	3,327	91,257	- 0 -	25,330	119,914
Dues and subscriptions	9,841	12,914	8,462	17,419	48,636
	2,054,095	4,968,832	941,812	794,248	8,758,987
Depreciation and amortization	8,252	22,192	7,194	3,685	41,323
	\$2,062,347	\$4,991,024	\$949,006	\$797,933	\$8,800,310
	23%	57%	11%	9%	100%



2017 ANNUAL REPORT

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS FOR YEAR ENDED DECEMBER 31, 2017

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
PUBLIC SUPPORT AND REVENUE:			
Public support:			
Contributions and grants	\$6,087,852	\$407,370	\$6,495,222
Net assets released from restrictions	1,095,956	(1,095,956)	- 0 -
Total public support	7,183,808	(688,586)	6,495,222
Government grants and other contract revenue	1,240,434	- 0 -	1,240,434
Revenue:			
Investment income	888,860	- 0 -	888,860
Other income	14,613	- 0 -	14,613
Special events	676,172	- 0 -	676,172
Total revenue	1,579,645	- 0 -	1,579,645
Total Public Support and Revenue	10,003,887	(688,586)	9,315,301
EXPENSES:			
Program services:			
Medical and scientific	2,062,347	- 0 -	2,062,347
Services to patients and families	4,991,024	- 0 -	4,991,024
	7,053,371	- 0 -	7,053,371
Supporting services:			
Administration and finance	949,006	- 0 -	949,006
Marketing and fundraising	797,933	- 0 -	797,933
	1,746,939	- 0 -	1,746,939
Total Expenses	8,800,310	- 0 -	8,800,310
CHANGE IN NET ASSETS	1,203,577	(688,586)	514,991
NET ASSETS, BEGINNING OF YEAR	7,244,941	1,815,054	9,059,995
NET ASSETS, END OF YEAR	\$8,448,518	\$1,126,468	\$9,574,986

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Because primary immunodeficiency diseases are rare, chronic conditions, continuity in our programs is one of the most important aspects of the services provided by IDF. 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. IDF greatly appreciates these sponsors and all others who make our mission possible.

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The Dominators	Unite and fight	Zany Zebras
The Gammatrons	University Hospitals Allergy / Immunology	Zebra Apocalypse
The Jean Team	US BIO Zebras On The Move	Zebra Cakes
The Rad Walkers	Vrieze Team	Zebra Squad
The Region 219	WALK TO A DIFFERENT	Zebra Wings
The Sub-Q-Tees	HOOFBEAT	Zebra Zombies
The Taters	Walking on the WILD side	Zebras in Tiaras
The Toothless Q Tips	We CANCERvive	Zink's Zippin Zebras!
The Tortoise and the Zebras	Wilson's Wonders	
The Zebrateers	Win For Quinn	
Timmy's Gators	Wonder walkers	
Tracy's Troops	Wright's in Stripes	
Tribe of Zebras	Young Dazzlers	
Troop Ramus		

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



Immune Deficiency Foundation ■ 110 West Road, Suite 300 ■ Towson, MD 21204 ■ 800-296-4433
www.primaryimmune.org ■ idf@primaryimmune.org