

2018 ANNUAL REPORT

BUILDING THE IDF COMMUNITY



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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.

Building the IDF community is ever evolving and constant. First and foremost we empower the IDF community with knowledge and resources. Since 1980, we have fulfilled the basic needs of those diagnosed with PI: information and support. When someone faces a diagnosis of PI, IDF is here for them and guides them when they have questions. We provide content and programming beyond the essentials that is relevant and meaningful to the community—no matter their specific diagnosis. We educate those living with PI about advocating for themselves, from treatment to insurance issues.

In 2018, our community grew stronger. We reached more people and promoted increased awareness of PI in the U.S and the world. We connected with those newly diagnosed and those who are not connected to IDF—but there are still more out there to reach. IDF serves as the voice of the PI community—we ask the tough questions and make sure our community is represented from public policy decisions to research opportunities.

Building the IDF community now and in the years to come is made possible by the generosity of donors. Thank you to all who supported IDF in 2018.

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.



17,470 patients and healthcare professionals reached with **224** presentations in **109** cities, **32** states and **3** countries.



100 healthcare professionals volunteered at **27** education meetings attended by **1,608** individuals.



292,379 education materials distributed at no cost to patients and families.

WORKING TOGETHER

Volunteers are the heart of what we do.

IDF Volunteer Network

We welcomed **211** new volunteers and **176** walk volunteers. This nationwide network of dedicated volunteers serves to advance the reach of IDF in areas of strategic importance of the PI community.

IDF Get Connected Groups

27 Get Connected Leaders of **26** Get Connected Groups in **11** states coordinated **74** get-togethers attended by **531** individuals. These groups are designed to connect individuals and family members living with PI in their local communities.

IDF Plasma Partner Program

Plasma partner volunteers made **56** visits to plasma centers, reaching a total of **2,353** people where they shared their stories with donors, adding a face and humanizing the experience of plasma donation.

IDF Peer Support Program

119 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.



UNITING THE COMMUNITY

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

IDF TEEN ESCAPE

IDF Teen Escapes 2018 were held in Minneapolis, MN (June 23-24) and Phoenix, AZ (July 14-15) with over **150** attendees, **60%** being first-time attendees. 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.

IDF WALK FOR PRIMARY IMMUNODEFICIENCY

In 2018, over **3,000** walkers from **16** cities and **345** teams came together and raised more than **\$884,500** 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.

IMMUNE DEFICIENCY FOUNDATION 2018 IDF RETREATS

IDF Retreats are weekend gatherings for everyone in the PI community – patients, parents, siblings, partners and children. In 2018, the IDF Retreats were held in Cleveland, OH and St. Augustine, FL. Between both retreats there were a total of **485** attendees, **175** being their first retreat, and **140** being their first IDF event.

OPTIMIZING THE ONLINE USER EXPERIENCE

Expanding the content and functionality of our website.



Website - The Go-to-Resource for the PI Community

More than 782,345 users accessed primaryimmune.org. The website design offers a streamlined and intuitive experience for the user.



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.

1,258

requests were submitted by patients and families who needed help locating specialists

With this in mind, IDF launched a new feature called the **Physician Finder**. Users can log into their account and find a specialist right in their area. The service includes more than 2,600 clinicians.

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.

7,054

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.

1,804

people and healthcare professionals participated in 2 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.

4,077

IDF ePHR health records with

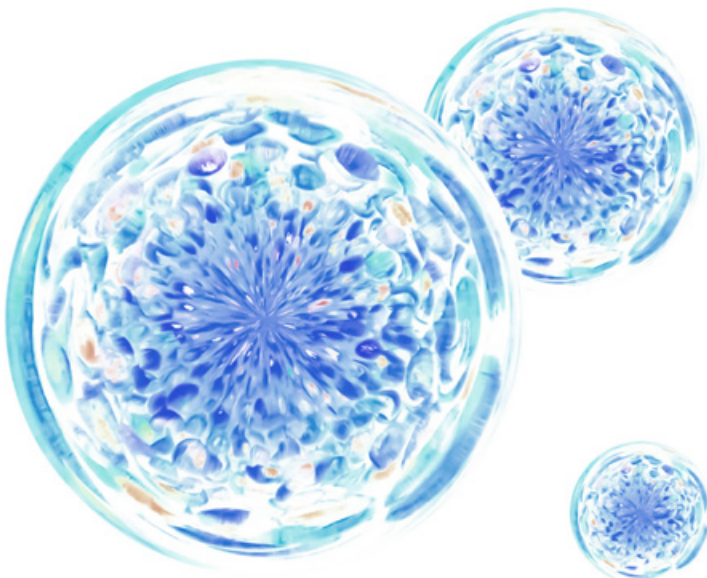
2,247

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.



MEDICAL OUTREACH



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

In 2018, IDF contacted over **2,900** medical professionals in the U.S. and Puerto Rico, we exhibited at **6** medical conferences, and provided **91** physicians expert consults through our Consulting Immunologist Program. This program 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 and TZ Social Media Stats

At the end of 2018, we had **15,878** Facebook likes; **2,876** Twitter followers; **2,117** Instagram followers; and **6,946** users on IDF Friends. TZ, the IDF Zebra had **787** Twitter followers and **745** Instagram followers. The IDF Walk for PI Facebook had **3,224** likes.

National Primary Immunodeficiency Awareness Month and World PI Week

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**.

Newsletter and E-newsletter

30,000 individuals received the IDF newsletter, IDF ADVOCATE. **27,000** individuals received the monthly e-newsletter, Primary Immune Tribune.

IDF Resource Center

For all videos on the IDF Resource Center, they were watched more than **2,093** times. IDF uploaded **10** new videos to our YouTube channels circulating over **91,613** views. A podcast called Primary Immunodeficiency Q&A was launched, with **4** different episodes played over **1,173** times.

PUBLIC POLICY

The voice of the PI community.



IDF Action Alerts

2,000 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.



Advocacy Day 2018

In 2018, **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.



SCID Newborn Screening Campaign

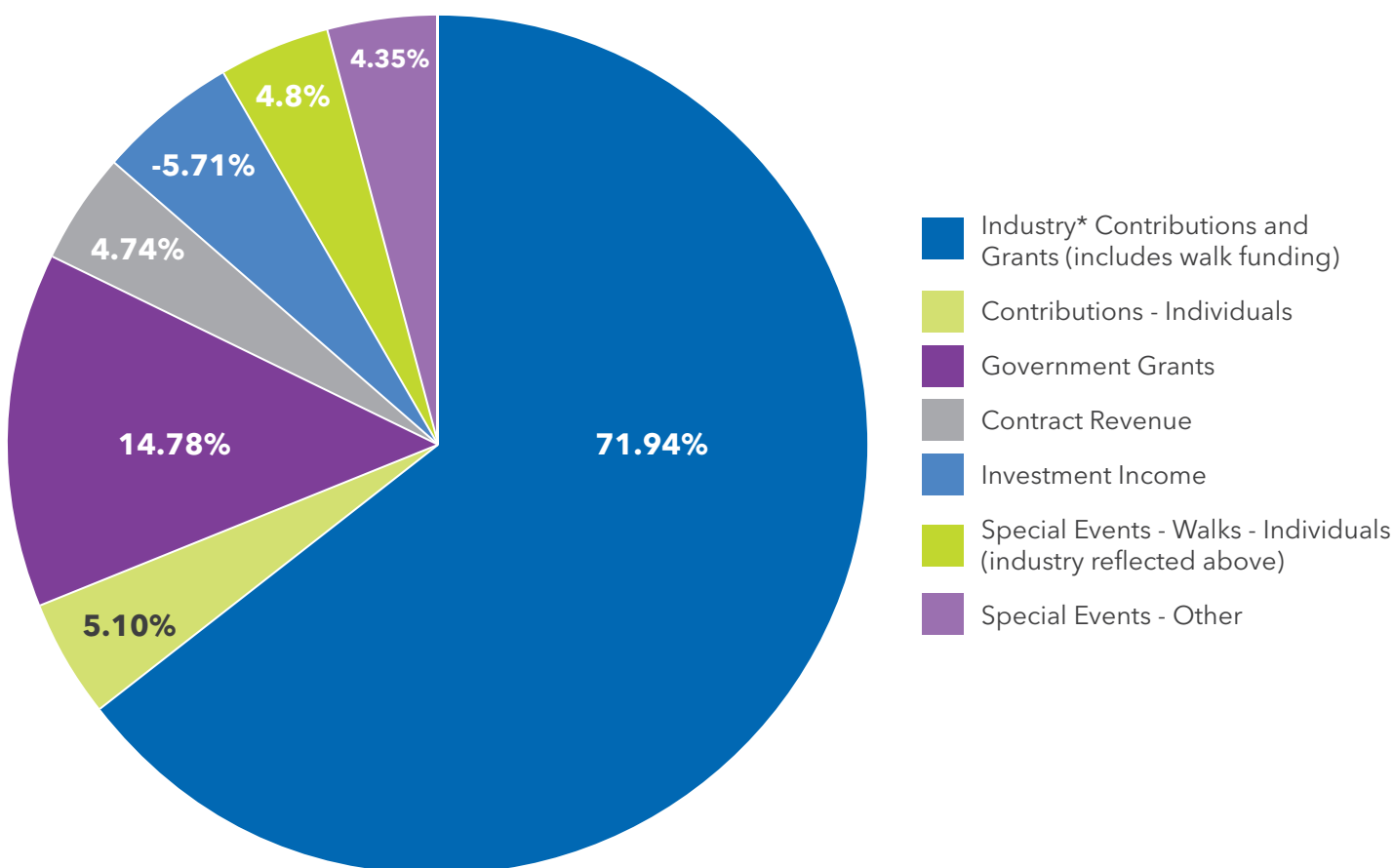
Much progress was made in 2018 to ensure all babies born in the U.S. are screened for Severe Combined Immunodeficiency (SCID), one of the most severe forms of PI. All **50** states in the U.S. are now screening for SCID. IDF will continue to actively support and educate families affected by SCID.

REVENUE

FOR THE YEAR ENDING DECEMBER 31, 2018

Industry* Contributions and Grants (includes walk funding)	\$4,290,627	71.94%
Contributions - Individuals	\$304,167	5.10%
Government Grants	\$881,608	14.78%
Contract Revenue	\$282,827	4.74%
Investment Income	(\$340,481)	-5.71%
Special Events - Walks - Individuals (industry reflected above)	\$286,250	4.8%
Special Events - Other	\$259,446	4.35%
Total	\$5,964,444	100%

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



STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2018

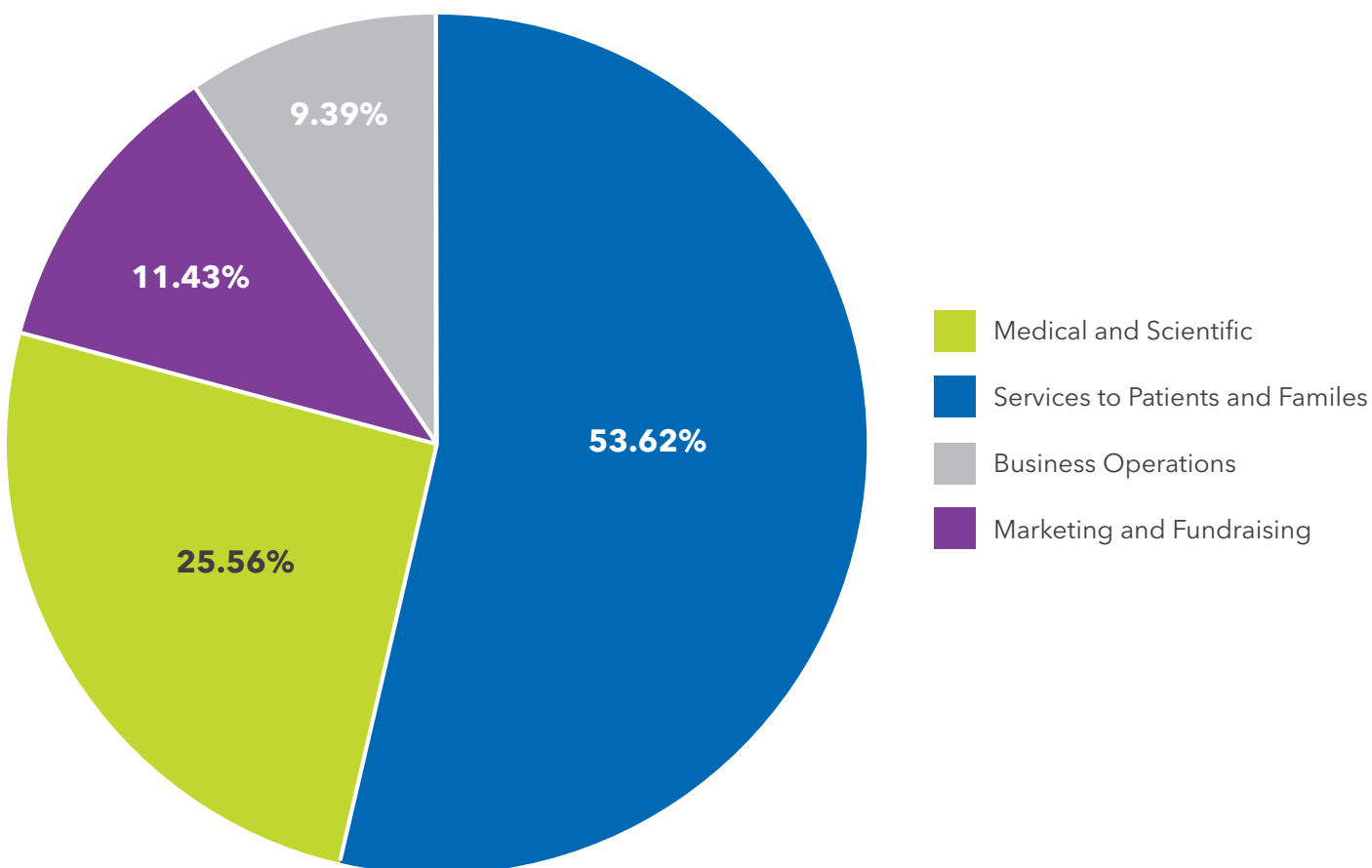
	PROGRAM SERVICES		SUPPORTING SERVICES		TOTAL
	MEDICAL & SCIENTIFIC	SERVICES TO PATIENTS & FAMILIES	ADMINISTRATION & FINANCE	MARKETING & FUNDRAISING	
Salaries	\$599,773	\$1,350,432	\$351,256	\$310,355	\$2,611,816
Employee Benefits	\$73,911	\$151,457	\$54,049	\$37,549	\$316,966
Payroll Taxes, etc.	\$48,528	\$107,025	\$26,832	\$25,683	\$208,068
Total	\$722,212	\$1,608,914	\$432,137	\$373,587	\$3,136,850
Professional Fees	\$560,503	\$885,205	\$123,573	\$64,599	\$1,633,880
Training, Conference, Conventions & Meetings	\$51,463	\$588,666	\$66	\$184,572	\$824,767
Travel	\$46,318	\$108,153	\$2,338	\$17,389	\$174,198
Awards and Grants	\$215,437	\$17,850	\$0	\$0	\$233,287
Occupancy	\$35,935	\$179,537	\$33,510	\$26,593	\$275,575
Insurance	\$9,041	\$16,467	\$4,360	\$3,459	\$33,327
Printing and Publications	\$19,467	\$41,212	\$827	\$21,691	\$83,197
Telephone	\$8,258	\$27,533	\$5,029	\$3,771	\$44,591
Postage and Shipping	\$36,057	\$81,899	\$3,276	\$25,092	\$146,324
Supplies	\$10,593	\$40,452	\$6,073	\$6,760	\$63,878
Rental and Maintenance of Equipment	\$4,011	\$33,876	\$9,892	\$2,960	\$50,739
Miscellaneous	\$12,010	0	\$10,721	\$6,485	\$29,216
Advertising	\$536	\$5,659	\$0	\$16,745	\$22,940
Dues and Subscriptions	\$10,790	\$19,271	\$6,608	\$26,372	\$63,041
Total	\$1,742,631	\$3,654,694	\$638,410	\$780,075	\$6,815,810
Depreciation Amortization	\$11,848	\$25,644	\$5,831	\$4,627	\$47,950
Grand Totals	\$1,754,479	\$3,680,338	\$644,241	\$784,702	\$6,863,760

STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2018

EXPENSE

Medical and Scientific	\$1,754,479	25.56%
Services to Patients and Families	\$3,680,338	53.62%
Business Operations	\$644,241	9.39%
Marketing and Fundraising	\$784,702	11.43%
Total	\$6,863,760	100%



STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

FOR THE YEAR ENDING DECEMBER 31, 2018

	WITHOUT DONOR RESTRICTIONS	WITH DONOR RESTRICTIONS	TOTAL
PUBLIC SUPPORT AND REVENUE			
Public Support			
Contributions and Grants	\$3,992,224	\$672,570	\$4,594,794
Net assets released from restrictions	\$1,305,959	(\$1,305,959)	\$0
Total public support	\$5,228,183	(\$633,389)	\$4,594,794
Government Grants and Other Contract Revenue	\$1,164,435	\$0	\$1,164,435
Revenue			
Investment Loss, Net	(\$340,481)	\$0	(\$340,481)
Other Income	\$1,320	\$0	\$1,320
Special Events	\$544,376	\$0	\$544,376
Total Revenue	\$205,215	\$0	\$205,215
Total Public Support and Revenue	\$6,597,833	(\$633,389)	\$5,964,444
EXPENSES			
Program Services			
Medical and Scientific	\$1,754,479	\$0	\$1,754,479
Services to Patients and Families	\$3,680,338	\$0	\$3,680,338
Total Program Services	\$5,434,817	\$0	\$5,434,817
Supporting Services			
Administration and Finance	\$644,241	\$0	\$644,241
Marketing and Fundraising	\$784,702	\$0	\$784,702
Total Supporting Services	\$1,428,943	\$0	\$1,428,943
Total Expenses	\$6,863,760	\$0	\$6,863,760
Change in Net Assets	(\$265,927)	(\$633,389)	(\$899,316)
Net Assets, Beginning of the Year	\$8,448,518	\$1,126,468	\$9,574,986
Net Assets, End of Year	\$8,182,591	\$493,079	\$8,675,670

LEADERSHIP



Pictured, from left: J. Seymour, C. Demaret, J. Smith, T. Halper, R. Buckley, C. Lage, K. Sullivan, B. Rath, B. Ballard, S. Fietek, A. Walsh, R. Low, J. Buckberg, J. Boyle, T. Shaw, Y. Shorten

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Pictured, from left, front row: E. Garabedian, L. Anastasia, C. Hill Dansereau, M. Hintermeyer, L. Lentini. From left, back row: M. E. Younger, K. Epland, W. Blouin, C. Duff, L. Lyter-Reed.

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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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CSL Behring
Grifols
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Local Walk Supporters

Platinum Supporter

Haemonetics (1 Walk)

Gold Supporters

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Kedrion Biopharma (1 walk)
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US Bioservices (6 walks)

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Thank you to the following organizations and individuals for supporting IDF!

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Abbie Employee Giving Program
Aetna Foundation
American Express Charitable Fund
Anthem
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AT&T United Way/ Employee Giving Campaign
Aon Foundation
Axa Foundation

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MATCHING GIFT & PAYROLL DEDUCTION COMPANIES (cont.)

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 The Walt Disney Company Foundation
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 Wonderful Giving
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IDF WALK FOR PI TEAMS (A-Z)

"Gott" a Cure?
 #GRACIESTRONG
 #ourtrooper

#teamHailey
 A&I and Hope&Will
 Aaron's Walk in the Park
 Abasi's Tribe
 Abbie's Herd
 Accredo Healthcare
 Accredo Specialty Pharmacy
 Addy's Army
 Advocate Children's Hospital
 AHG
 Aj's Team
 Alanna's Angels
 Allergy Partners of NT
 Alyssa's Angels
 Anna's Angels
 Anti-Bodies in Motion
 Ashley's CVID Fighting Force
 Avery's Avengers
 Ballistic Boxer
 Bean Squad
 Between a Walk and a Hard Place
 BioLife HQ
 BioLife Plasma Services
 BioLifeSavers
 BPL Plasma
 BPL Plasma Cleveland
 Brady's Warriors
 Brandy's Herd
 Brave
 Brockin' Zebras
 Bruno's Brigade
 Building Bridges
 Carol's Closet Crusaders
 Carranza Strong
 Carter's Crew
 Cashton's Team
 Central GA Z's
 Chelsea's Herd
 Children's Hospital and Medical Center
 Children's Mercy Immunology
 CHM Ambulatory Infusion Center
 CHofSA
 CHOP PI PATROL
 Chuck's Champs
 Complete Infusion Services
 Cooper's Crusaders
 Corrin's Team
 Courageous Zebras

Covington's Team
 CSL
 CSL 0132
 CSL ATLANTA
 CSL BEHRING NORTHEAST
 CSL Boston
 CSL Dallas
 CSL Ft Lauderdale
 CSL Plasma - Kimple Area 2018
 CSL Plasma Illinois
 CSL Plasma Indy
 CSL Plasma Pennsylvania
 CSL Plasma Warriors
 CSL St. Louis
 CSL Tampa
 CSL Chicago
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 Dare to Hit the Wahl
 Debbie's Team
 Dinocharge
 Dorian's Dream
 Elijah's Warriors
 Emma's Chai for Dad
 ENT and Allergy Associates CARE
 Ethan's herd
 Fellows of the Bob 2018
 Frankie's friends
 Gabby's Team
 Gavin's Jedi
 Glennon's Zebras
 Globe Trotters
 Goldies Over 55
 Good
 Good's Gang
 GotLeiker
 Gracie Strong
 Grifols
 Guin's Gobulins
 Haemonetics
 Hafetz and Associates
 Holiday Team
 Hailey's Superheroes
 Halper's Helpers
 Harriet's Zebra Angels
 Hart & Soul
 Heidi's Heroes
 Heroes, Cops and Kids - STL
 Honor 4 Conner

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IDF WALK FOR PI TEAMS (A-Z) (cont.)

Horizon Pharma	Mind Over Miles - CSL Plasma DFW	Team Accredo Healthcare	Team Longevity
IDF Awesome	Misha's Crew	Team Addie and Kenzie	Team Lukas & Danny
Immunology Warriors	New Life Pharmacy & Medical Supply	Team Aidan	Team Lyndsey
In it 4 the cause	Nichole's Purple Zebras	Team AIR Care	Team Mass General Hospital
Incredible Jaiden: Be Strong	Norcal Primary Immune Deficiency	Team Andrew	Team Matilda
Intactivists	Northwell Allergy & Immunology	Team Athena	Team McStripes
Isa is a Fighter	Oak Park Trailblazers	Team Baby Grace	Team Mighty Quinn
Isabella's Immunogladiators	Octa Stars	Team Baylee	Team Mitchell
Jaidyn's Crew	Octapharma	Team Ben	Team Monica
Jared's Warrior	O'Fallon 224	Team Boyle	Team Nate
JDCH Allergy and Immunology	On Your Marks	Team Brigham	Team Naughton
Jeni's Journey	Owen's Herd	Team Brittany	Team Naveyah
Jenkins	PI WALKERS	Team Caeden Strong	Team Nazir
Jessica's Amazing Zebras	Pink Zebras	Team Caleb	Team Nolan
Jodi's Team	Pippi's & Mimi's Zebra Zoo	Team Charlotte	Team NY
Kaeser's Krew	Pivot Design	Team Cip	Team PACE Yourself!
Kailey's Superheroes	Plasma Warriors	Team Clint	Team Palmer
Kanarek Allergy Asthma Immunology	Platinum Zebras	Team Cream	Team Pate
KEDPLASMA USA	Rashann's Stampede	Team Crisp (Germ Busters)	Team Peralto
Kent's Zebra	Reisman Rocks	Team CSL Atlanta	Team Pig Pen
Kim's glam squad	Rimmer Zebras	Team CSL Behring Philly	Team Plasma
kittykatstripes	Samantha's Herd	Team CSL Boca	Team Porch For Primary Immunodeficiency
Konner's Zebra Krew	Sandra's Dazzles	Team CSL Cleveland	Team Princess Leah
Kroger Specialty Infusion	Sara Strong	Team CSL Detroit	Team Rath
K'S ZANY ZEBRAS	Savanna's Herd	Team CSL DFW	Team Redline
Kyler's Cavaliers	Schroeder	Team CSL KC	Team Riley
Lainey's Krew	SCID, Angels for Life	Team CSL Roseville	Team Ropes
Laura's Awesome Zeb	See Jane Walk	Team CuKo	Team Samantha
Life with Liam	Sherry's Herd	Team Dallas	Team Sean
Life with stripes	Shire	Team Dean	Team Shari Rankert
Lincoln Park CSL Plasma	Shire - Los Angeles	Team DeVos	Team SMurphy
Linda Tepe	ShortChop	Team DWJ	Team Somara
LoganZillas	Sky Blue Pink	Team Emersen	Team StuPlfy
Lucas' Super Squad	Skywalkers	Team Enzyvant	Team Superman
Luke's Linebackers	Smith Family	Team Evan	Team Tarulli - The Inner Circle
Lu's Fighting Zebras	Southern Zebras	Team Ferreira	Team Teach
Maddie's Herd	Sprayberry	Team Giovanna	Team Teflon
MAGIS	St. Louis 132	Team Graber	Team Tishomingo
Making Strides for PI	St. Louis Children's Hospital & Wash U	Team Hayden	The BA-Team
Mandy's Immune Platoon	Stefanie's Platelet Posse	Team Herd of Turtles	The Fighting Condons
Marcy's Miracles	Stephen's Strollers	Team Highland Park	The Gradiators
Maverick's Mission	Strides for Sophie	Team Hope	The Herd
MBM313	Stripes & Strides	Team Isabella	The Jay Nytro Group
McGlover	Stripes and All	Team Joel	The Jean Team
McPhee	Summer's Stars	Team Jordan	The Konen Connection
Michael Blair #MBM313	Suzi's Sneakerz	Team Karlie	The Plasma Posse
Michelle	Syd's Soldiers	Team Kedrion BioPharma	The Red Stripes
Mighty Mighty Mason	Tami's Stampeding Zebras	Team Keegan	The Rogers Crew
Miles for Madison	Tara's Team	Team Kegan-Gatesville Zebras	THE SCID WARRIOR
	Taylor's Herd	Team Kelso	The Sub-Q-Tees
		Team Liam	The Toothless Q Tips
		Team Linzebra	
		Team Lois	

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Zebra's Eye
Zebras in Tiaras
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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.

Thank You!



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