2018 At-A-Glance

THE VOICE OF THE PI COMMUNITY

Advocacy Day 2018

Making Our Voices Heard

- 49 Patients/family members participated in
- 80 Legislative meetings

- 2,000 Letters and calls to policymakers as a result of IDF Action Alerts

Education Meetings

- 100 Healthcare professionals volunteered at
- 27 Education Meetings, attended by
- 1,608 individuals, where an average of
- 48% of the attendees were first-time attendees

292,379 Education Materials distributed at no cost to patients & families

Educational Presentations

- 17,470 Patients & healthcare professionals reached
- 224 Presentations
- 109 Cities
- 32 States
- 3 Countries

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100% of all babies born are now being screened for SCID in U.S!

All 50 States are currently screening for SCID as of January 2019
Medical Outreach

2,900 Medical Professionals contacted in the U.S. and Puerto Rico
6 Medical conference exhibits
91 Physician expert consults through our Consulting Immunologist Program

IDF PATIENT SURVEYS
1,804 People and healthcare professionals participated in 2 major, patient-focused IDF surveys

IDF TEEN ESCAPE
Minneapolis, MN June 23 – 24, 2018
Phoenix, AZ July 14 – 15, 2018
150 Attendees 60% were first-time attendees

IDF Volunteer Network

211 New volunteers
176 Walk volunteers

Volunteers created awareness and distributed thousands of educational materials and spoke to approximately

2,353 People during
56 visits to plasma centers

IDF Peer Support volunteers offered one-on-one support to 119 individuals

Cleveland, OH July 20-22, 2018
192 attendees Was the first IDF Retreat for 60 attendees Was the first IDF event for 55 attendees
St. Augustine, FL August 10-12, 2018
293 attendees Was the first IDF Retreat for 115 attendees Was the first IDF event for 85 attendees

Raised more than $300,000
And with sponsor funds, more than $884,500!
2018 At-A-Glance

Get Connected Groups

Support through Community

27 Get Connected Leaders
26 IDF Get Connected Groups
in 11 states
coordinated 74 get-togethers
attended by 531 individuals

IDF Social Networks:
As of January 31, 2019

IDF ePHR & IDF PI CONNECT
4,077 IDF ePHR health records
2,247 IDF PI CONNECT participants

IDF Friends
6,946 Members
15,878 Likes
2,117 Followers
2,876 Followers
1.29 Million views
986 Followers

TZ’S Social Networks:
As of January 31, 2019

IDF Resource Center
for all of our videos was watched more than
2,093 times with 10 new videos
created, circulated over 91,613 views

INNOVATING THROUGH PATIENT-POWERED RESEARCH

Also launched this year
Primary Immunodeficiency Q&A
with 4 episodes which were played over 1,173 times

USIDNET
7,054 Registered
As we look back on 2018, we find it useful to review the statistics behind our initiatives as we plan for the year ahead. With each project, we are upholding our dedication to improving the diagnosis, treatment and quality of life of persons living with primary immunodeficiency diseases.

In 2018:

The IDF SCID Newborn Screening Campaign saw the last 4 states begin to screen. As of January 2019, all 50 states are screening for SCID, covering 100% of all births in the nation. IDF Advocacy Day on Capitol Hill resulted in approximately 49 patients and family members participating in over 80 Congressional meetings. Throughout the year, IDF Action Alerts generated over 2,000 letters and calls to policymakers.

100 healthcare providers volunteered to present at 27 Education Meetings attended by 1,608 individuals, where an average of 48% of the attendees were first-time attendees.

17,470 patients and healthcare professionals attended more than 224 IDF educational presentations in 109 cities, 32 states and 3 countries.

More than 292,379 IDF educational materials were distributed to members of the PI community.

The IDF newsletter, published two times, had a circulation of over 30,000. The monthly e-newsletter was sent to more than 27,000. More than 782,345 users accessed primaryimmune.org.

IDF’s patient advocacy services helped fulfill over 9,732 requests from patients and families seeking education, information and assistance. The #1 need was for help to locate a specialist with over 1,258 requests. With this in mind, IDF launched a new feature in 2018—the Physician Finder. Users can log into their account and find a specialist in their area. The service includes more than 2,600 clinicians.

As part of our medical outreach, we contacted over 2,900 medical professionals in the U.S. and Puerto Rico, we exhibited at 6 medical conferences, and provided 91 physician expert consultations through our Consulting Immunologist Program.

IDF national patient surveys provided crucial insight into the personal impact of PI, and more than 1,804 people and healthcare professionals participated in 2 IDF surveys.

150 individuals attended two IDF Teen Escapes in Minneapolis, MN from June 23-24 and in Phoenix, AZ from July 14-15. Over 60% of the parents and teens were first-time attendees.

IDF Retreats were held in Cleveland, OH with 192 attendees, 60 being their first retreat and 55 being their first IDF event, and St. Augustine, FL with 293 attendees, 115 being their first retreat and 85 being their first IDF event.

Over 3,000 walkers from 345 teams in 16 cities helped raise more than $300,000 for IDF Walk for Primary Immunodeficiency and when sponsor funds are included, more than $884,500 was raised. National Walks were held in Atlanta, Boston, Chicago, Cleveland, Dallas, Fort Lauderdale, Kansas City, Los Angeles, New York City, Philadelphia, St. Louis and Tampa. Community Walks were held in Detroit, Indianapolis, Omaha and San Antonio. The Virtual Walk allowed participants to join regardless of where they lived.

The IDF Volunteer Network welcomed 211 new volunteers and 176 walk volunteers. Our network of volunteers created awareness campaigns in their area to recruit and raise awareness about plasma donations, reaching a total of 2,353 people during 56 visits to plasma centers. 119 individuals were offered encouragement from Peer Support Coaches.

27 Get Connected Leaders from 26 IDF Get Connected Groups in 11 States coordinated 74 gatherings, which were attended by 531 individuals.

Our social networking site IDF Friends continued to grow with over 6,946 members. The IDF Resource Center for all of our videos was watched more than 2,093 times. We uploaded 10 new videos to our YouTube channels circulating over 91,613 views, and we launched a podcast called Primary Immunodeficiency Q&A, with 4 different episodes played over 1,173 times.

IDF ePHR, our electronic personal health record specifically developed for individuals and families living with PI, increased awareness campaigns in their area to recruit and raise awareness about plasma donations, reaching a total of 2,353 people during 56 visits to plasma centers. 119 individuals were offered encouragement from Peer Support Coaches.

The United States Immunodeficiency Network (USIDNET), a program of IDF, is a network of leading immunologists who have joined together to advance knowledge in the field of PI. A key component is the patient-consented registry, which included 7,054 patients.