PATIENT SERVICES

PEOPLE LIVING WITH PI ARE SEARCHING FOR ANSWERS

1,781 New Patients
17,042 Total Patients

PATIENT REQUESTS

2014

2015

+500%

EDUCATION MEETINGS

- 27 MEETINGS
- 1,643 ATTENDEES
- 121 SPEAKERS

NEW PROGRAM!

IDF DIRECT

- LAUNCHED OCTOBER 1, 2015
- OVERWHELMINGLY POSITIVE RESPONSE
- PERSONALIZED INTERACTIONS WITH PATIENTS

IDF 2015 NATIONAL CONFERENCE

NEW ORLEANS, LA
LARGEST EVER!

- 1,366 ATTENDEES
- 12 COUNTRIES
- 39 STATES
- 66 SPEAKERS
- Would recommend IDF2015 to others
- Said the Exhibitors were a Valuable Addition

TEEN PROGRAM

- 2 TEEN ESCAPES
- 177 ATTENDEES

IDF MEDICAL PROGRAMS

773 NEW HEALTHCARE PROFESSIONALS
FOR A TOTAL OF 6,292 CLINICIANS

Consulting Immunologist Program

IDF Healthcare Provider Outreach

- UP-TO-DATE CONTACT INFORMATION
- MORE CHOICES FOR LOCATING A PHYSICIAN

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VOLUNTEER NETWORK

DEVELOPED FORMAL VOLUNTEER PROGRAM
NEW OUTREACH INITIATIVE
NEW RECRUITMENT METHODS

PUBLIC POLICY

SUCCESSFUL NATIONAL ADVOCACY DAY

HR 1600 - 7 NEW COPRIOSORS
100 LEGISLATIVE MEETINGS

2 YEAR DELAY ON CADILLAC TAX

NEW GRASSROOTS ADVOCACY EFFORTS FUNDED FOR NV, FL & IN

IDF REMEMBERS

PLAQUE

IN MEMORY OF

RESEARCH

SURVEY RESEARCH

4 MANUSCRIPTS PUBLISHED

Health Insurance Survey

4 ABSTRACTS SUBMITTED TO CIS

USIDNET

INTEGRATION OF PI CONNECT DATA

RENEWED MECHANISM FOR FUNDING THE USE OF REGISTRY DATA FOR PUBLICATIONS

AWARDED FOR 5 YEARS IN ADMINISTRATIVE SUPPLEMENTS

IDF ePHR

+1,800 NEW USERS
LAUNCHED MOBILE APP

USIDNET

NEW HEALTH CALENDAR

PI CONNECT

RESEARCH FORUM WEBINARS

AWARDED 3-YEAR EXTENSION!
Immune Deficiency Foundation
2015 - Overview in Numbers

Our mission statement, affirming our dedication to improve diagnosis, treatment and quality of life for persons with primary immunodeficiency diseases, describes the goals of the Immune Deficiency Foundation (IDF). As we begin a new year, it is helpful to review the statistics behind our activities in 2015 as we start our work for the PI community in 2016.

In 2015:

Nearly 13,562 patients and healthcare professionals attended more than 184 IDF educational presentations in 105 cities in 32 states. The IDF 2015 National Conference in New Orleans drew more than 1,360 attendees.

IDF exhibited at 5 medical conferences as well as sponsored 7 LoBion Visiting Professor Programs as part of our medical outreach. 94 physicians utilized our Consulting Immunologist Program, and our online education course on Ig therapy for nurses issued its 550th certificate for this free, 5 credit course.

IDF ePHR, our electronic personal health record specifically developed for individuals and families living with PI, now has 2,290 health records. PI CONNECT, the IDF Patient-Powered Research Network, grew tremendously with 1,519 consented participants and was approved for a 3 year PCORI funding award.

Our nationwide network of volunteers created awareness by distributing thousands of educational materials and spoke to approximately 2,885 people during 89 visits to plasma centers. IDF Peer Support Volunteers offered one-to-one encouragement to 526 individuals.

Over 3,500 walkers from 378 teams in 11 cities helped raise more than $440,000 for IDF Walk for Primary Immunodeficiency and when sponsor funds are included, more than $1 million was raised. National walks were held in Boston, Cleveland, Fort Lauderdale, Greater Chicago, Houston, Los Angeles, Minneapolis, New York City, Philadelphia and the Nationwide Virtual Walk. 2 community walks were held in Charlotte, NC and Omaha, NE.

IDF Advocacy Day on Capitol Hill resulted in approximately 75 patients, family members and stakeholders meeting with over 100 members of Congress. 14 calls to action were sent to our community, generating over 4,000 letters and calls to policymakers. The IDF SCID Newborn Screening Campaign saw 7 more states begin screening and as of January 1, 2016, 34 states are screening for SCID.

IDF’s patient advocacy services helped fulfill over 6,600 requests from patients and families seeking education, information and assistance. Locating a specialist was the number one need with over 1,100 requests.

IDF national patient surveys provide crucial insight into the personal impact of PI and in 2015, more than 3,743 patients and healthcare professionals participated in 7 IDF surveys.

The IDF newsletter is published three times a year, has a circulation of over 40,000. The monthly e-newsletter is sent to nearly 30,000. Our website boasts a 62% increase in visits over 2014. Our social networking sites, IDF Friends and IDF Common Ground, continue to grow with nearly 5,000 members. Add to that, 2 active blogs and the IDF Video hub for all our videos, watched more than 303,120 times.

More than 190,000 IDF educational materials were distributed to members of the PI community.

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 surpassed the 4,000 registration mark. USIDNET was approved for 5 more years of NIAID funding.

Adding it all up—2015 was a productive year!

Join us in 2016 and help IDF continue to provide the services, education, information and advocacy that our community needs and so richly deserves.

110 West Road | Suite 300 | Towson, MD 21204 | 800-296-4433 | Fax 410.321.9165 www.primaryimmune.org | idf@primaryimmune.org

2015 A REMARKABLE YEAR FOR

RECOGNITION & LEADERSHIP

WHITE HOUSE CHAMPION OF CHANGE FOR PRECISION MEDICINE

4-STAR RATING FROM CHARITY NAVIGATOR

ADMINISTRATION

ACCOUNTING

Funding Approved!
LAUNCHED A NEW INTERNAL STAFF NEWSLETTER!
CREATED TRANSACTION FLOW BETWEEN DATABASES

COMMUNICATIONS

EXPANDED OUR SOCIAL PRESENCE SIGNIFICANTLY

INFORMATION TECHNOLOGY & DATABASE

DATABASE UPGRADE
CUSTOM DONOR REPORTS
REAL-TIME VALIDATION

WEBSITE IMPROVEMENTS
WEB FORM INTEGRATION

NEW PUBLICATION ORDERING SYSTEM

62.5% WEBSITE INCREASE FROM 2014

NC 3
National Conference
App, Website
e-Session Recordings

USIDNET: 5 more years
PI CONNECT: 3 more years

Using with
CGD Council Development Services

Leaders In:
IPOPI
World PI Week
NHC
A-PLUS
PBSA