



# Immune Deficiency Foundation

Presentation to the  
American Academy of Dermatology  
February 5, 2007



# Mission

- The national patient organization dedicated to improving the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy
- IDF is the first place to turn for help for patients and families





# IDF's Long Term Strategic Goals National in Scope

- Improve access to state-of-the-art medical care
- Enhance early diagnosis of PIDD
- Empower patients and families through education, information and peer support
- Expand scientific and medical research
- Increase the strength and reach of IDF



## IDF Today

- Founded 1980
- Board of Trustees
- Medical Advisory Committee
- Volunteer Network
- Professional Staff

250,000 individuals and their families in the U.S. diagnosed by PIDD



## IDF: Competencies

- Patient-centered
- Viewed as the resource for credible information for patients.
- Credibility and excellence of our information and programs
- Data: IDF has developed surveys that outline the treatment characteristics and experiences of our patients. This information has been critical in our interactions with the medical community, government, industry.
- Partnerships with the medical community, government agencies and industry

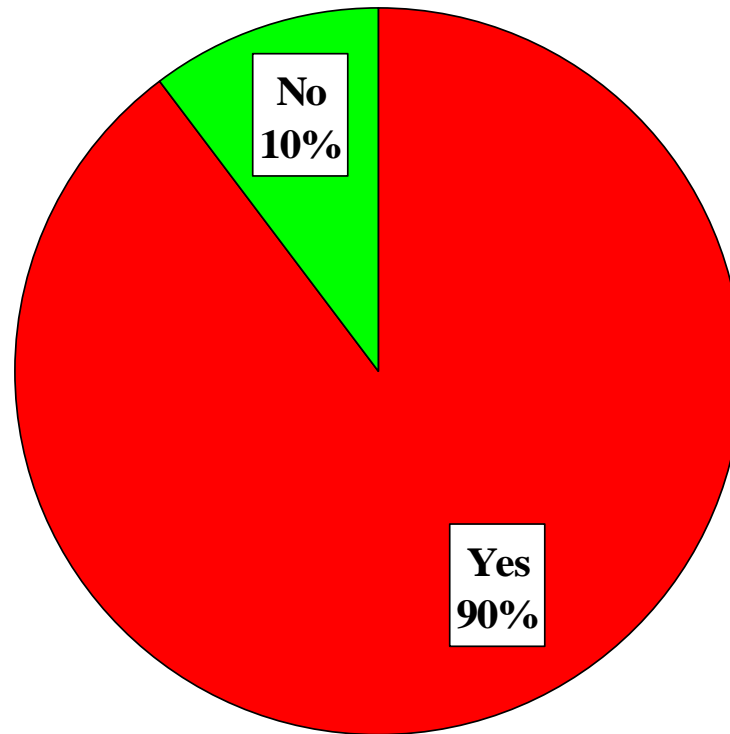


# IDF Survey of Patients using IVIG: 1997

Conducted among Patients from the First  
National Patient Survey (1996) who had been  
treated with IVIG



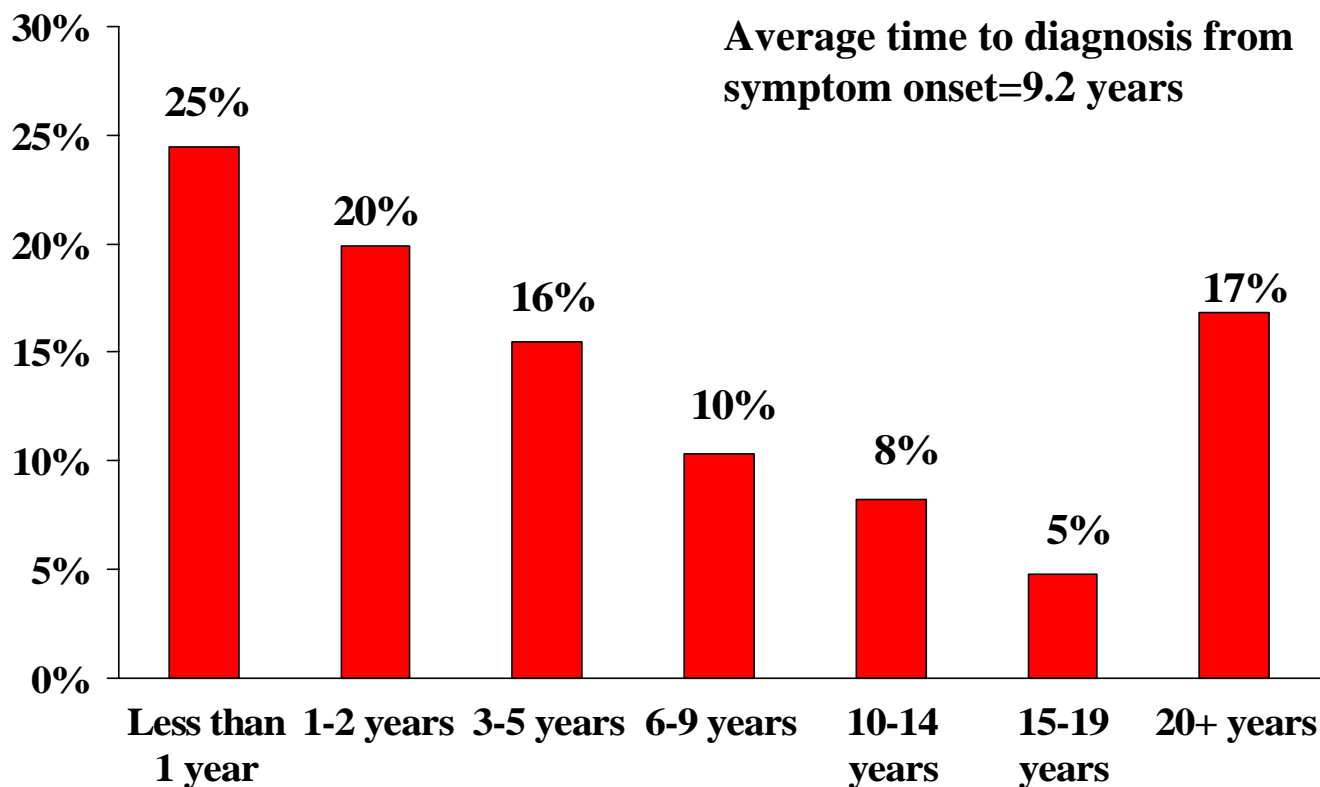
# Repeated or Unusual Infections Prior to Diagnosis



Q3. Did the patient exhibit repeated or unusual infections prior to diagnosis as immune deficient?  
N=908



# Time to Diagnosis After Symptom Onset



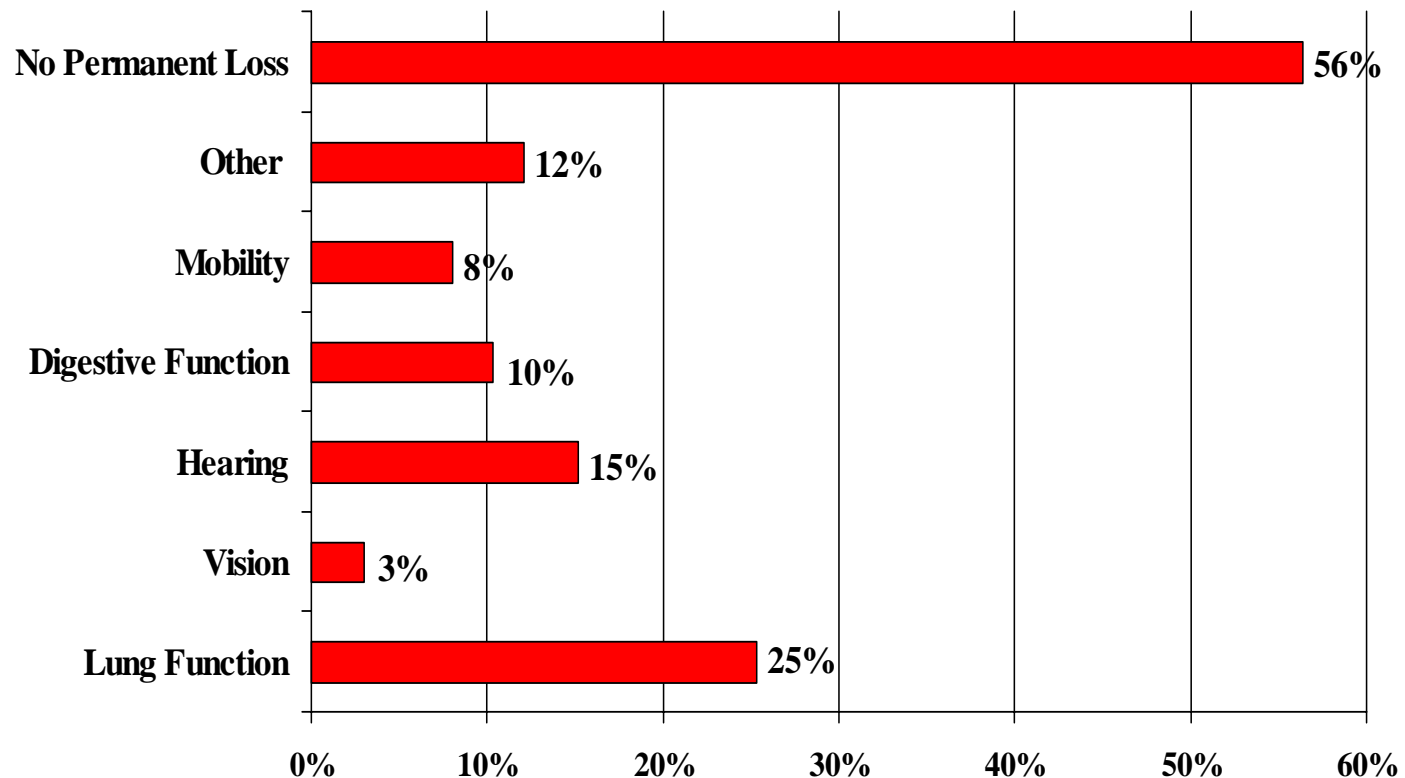
Q8. At what age (in years) was that person first diagnosed with a primary immune deficiency disease? Q12b. At what age (in years) did these repeated, serious or unusual infections begin?

(Base: N=1,397 – excludes those with missing information)





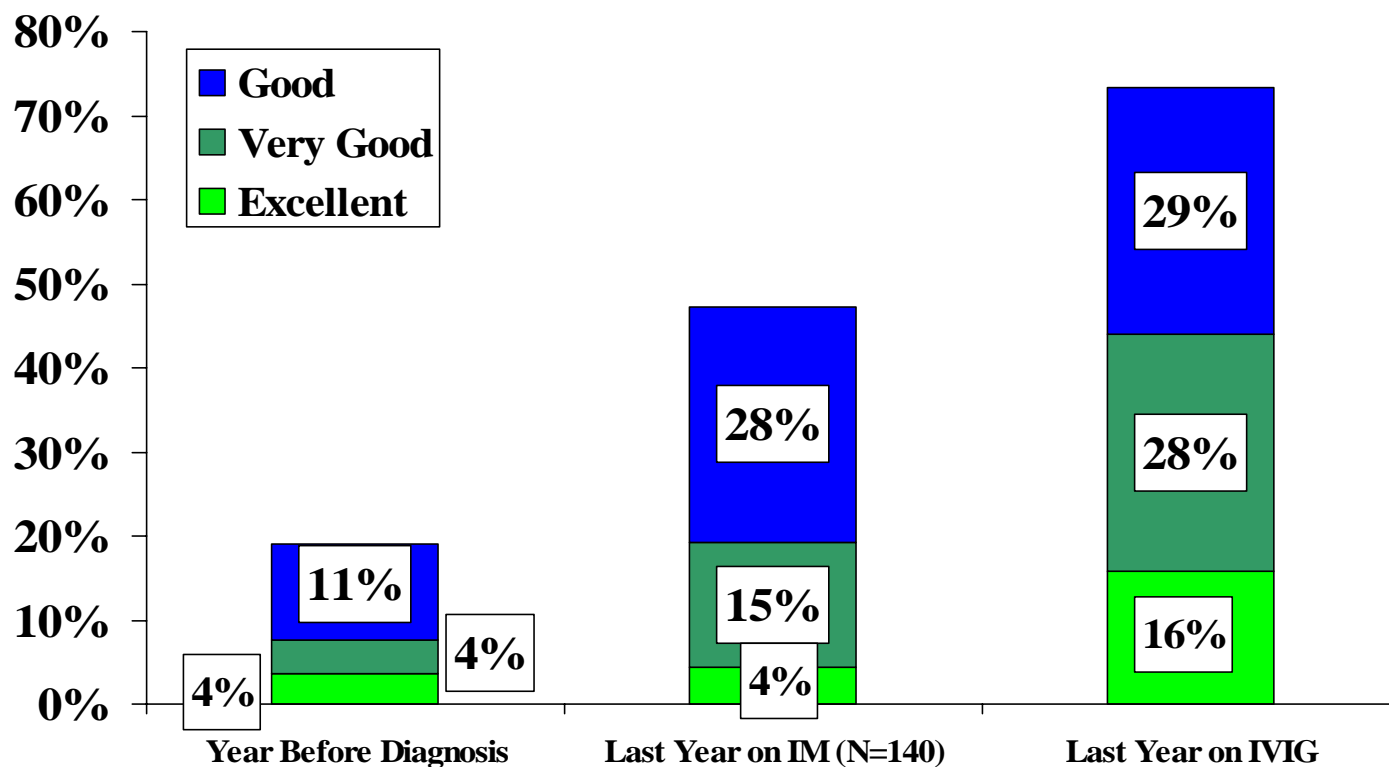
# Permanent Functional Impairment Prior to Diagnosis



Q5. By the time the patient was initially diagnosed as immune deficient, had he/she suffered any permanent loss of .....



# Health Status: Before and After Treatment



Q6/Q60. Overall, how would you describe his or her health (in the year prior to diagnosis/during the last year (on IM/IVIG)?



# Patient Services

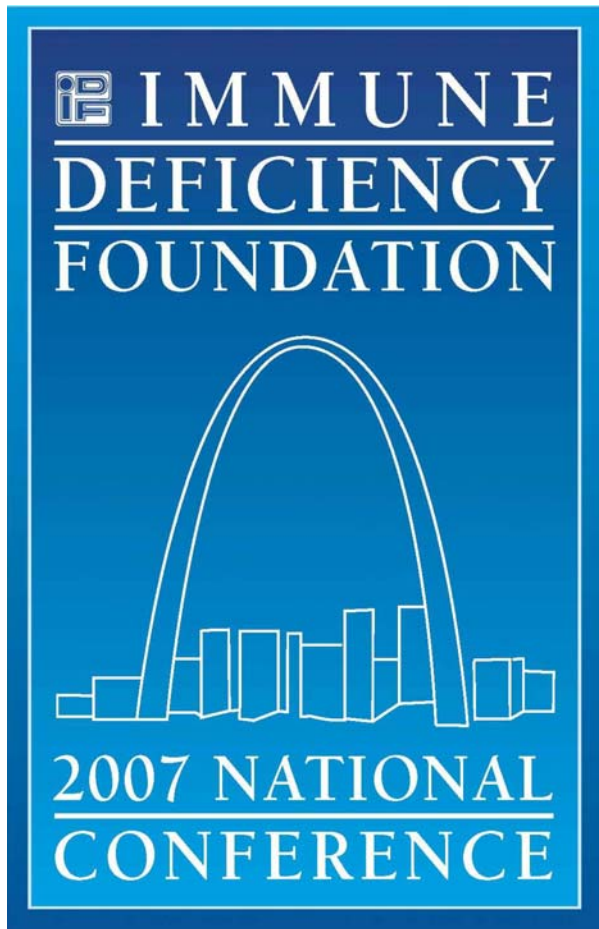


# Patient Education

- Local patient and family meeting
- Family weekend retreats
- Peer support
- Volunteer and staff organized



# 2007 IDF National Conference



St. Louis, Missouri

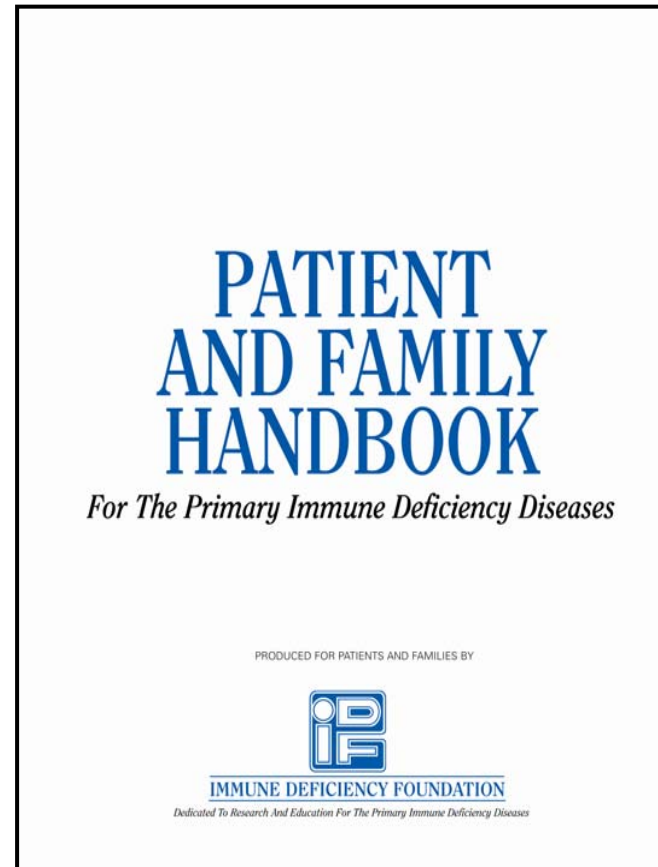
Renaissance Grand Hotel

June 28-30, 2007



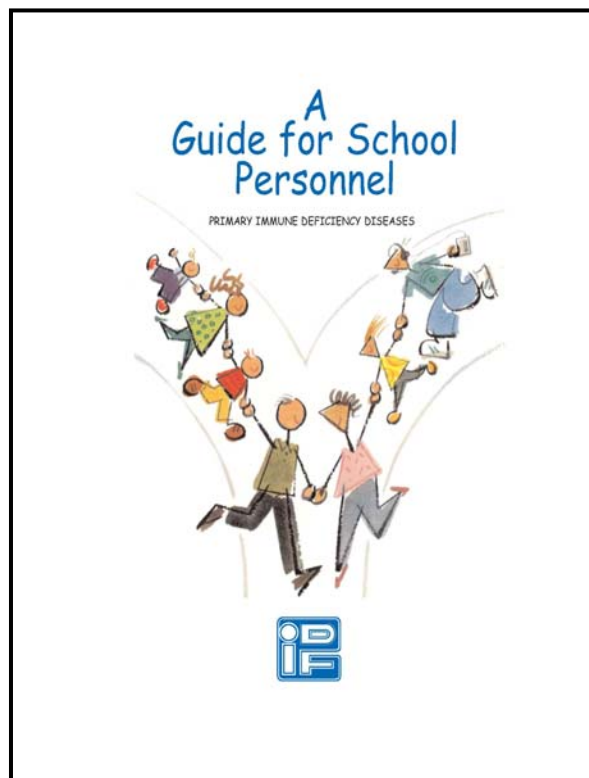
# Patient and Family Handbook

- 4<sup>th</sup> Edition under revision, to be unveiled at the 2007 National Conference in St. Louis





# A Guide for School Personnel





# Volunteer Network





# IDF Volunteer Network

## 200 volunteers nationwide

### Peer Contact Volunteers

- 37 states represented
- Over 600 peer support connections yearly
- Local patient education meetings

### Fund Raising Volunteers

- National and local fundraising efforts

### Grassroots Advocacy Volunteers

- Federal and state advocacy

Guidelines and training, with a staff member overseeing the network



# Communications



[www.primaryimmune.org](http://www.primaryimmune.org)

## Monthly IDF Web Site Activity

	Hits - Entire Site	Hits – Avg. Per Day	Unique Visitors	Visitors More Than Once
Monthly Average	967,5000	33,000	19,000	44,000



# IDF Communications



- IDF Advocate
- Circulation over 20,000
- Published 3 times a year



- E-Newsletter - Circulation 4,555
- Sent monthly
- Started October 2006



# Patient Advocacy and Public Policy



## Access to IVIG

- Patients have suffered serious issues of access to IVIG as a result of Medicare reimbursement reductions
- Since January 1, 2005 IDF has received hundreds of calls concerning treatment problems related to Medicare reimbursement for IVIG
- Calls from patients, clinicians, home health care companies and sites of care



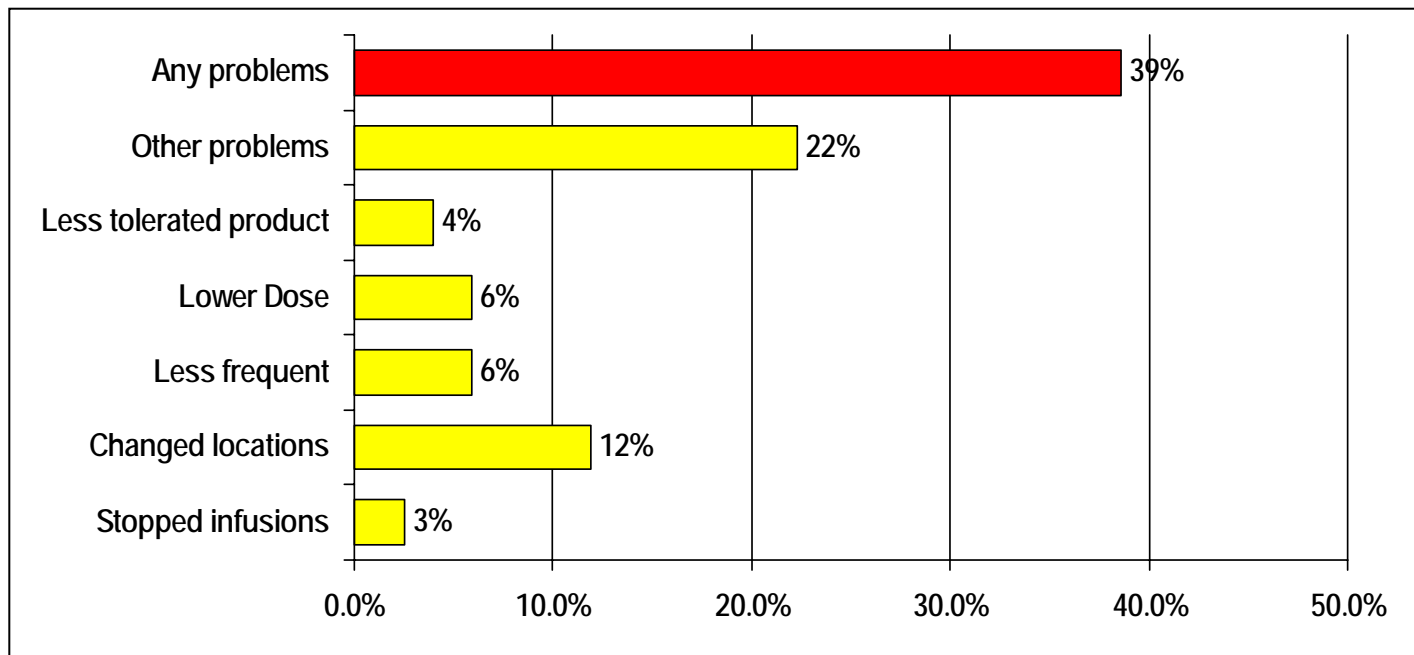
## IDF Strategies 2005

- In 2005 IDF conducted 2 surveys to quantify the impact of reimbursement reductions
  - Physician Survey
  - Patient Survey
- Partnered with industry, AAAAI and other patient organizations to advocate on Capitol Hill and with CMS and FDA



# Inadequate reimbursement is adversely affecting IVIG users

- Since 2005, 39% of PID patients on Medicare have experienced a wide variety of IVIG treatment problems\*



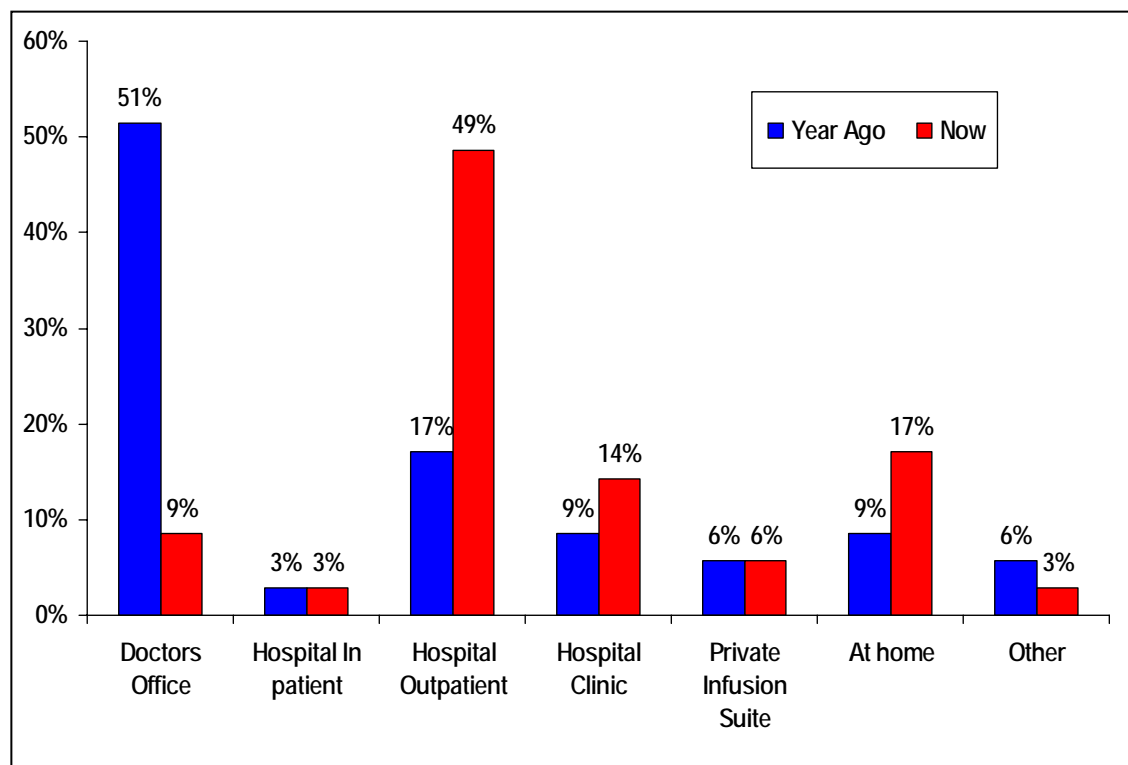
- Of the patients experiencing problems getting IVIG in the past 12 months, 40% say their health has been negatively affected.

\*Source: The Immune Deficiency Foundation 2005 telephone survey of Medicare Patients.





# To date, 12% of Medicare patients have changed their site of infusions\*

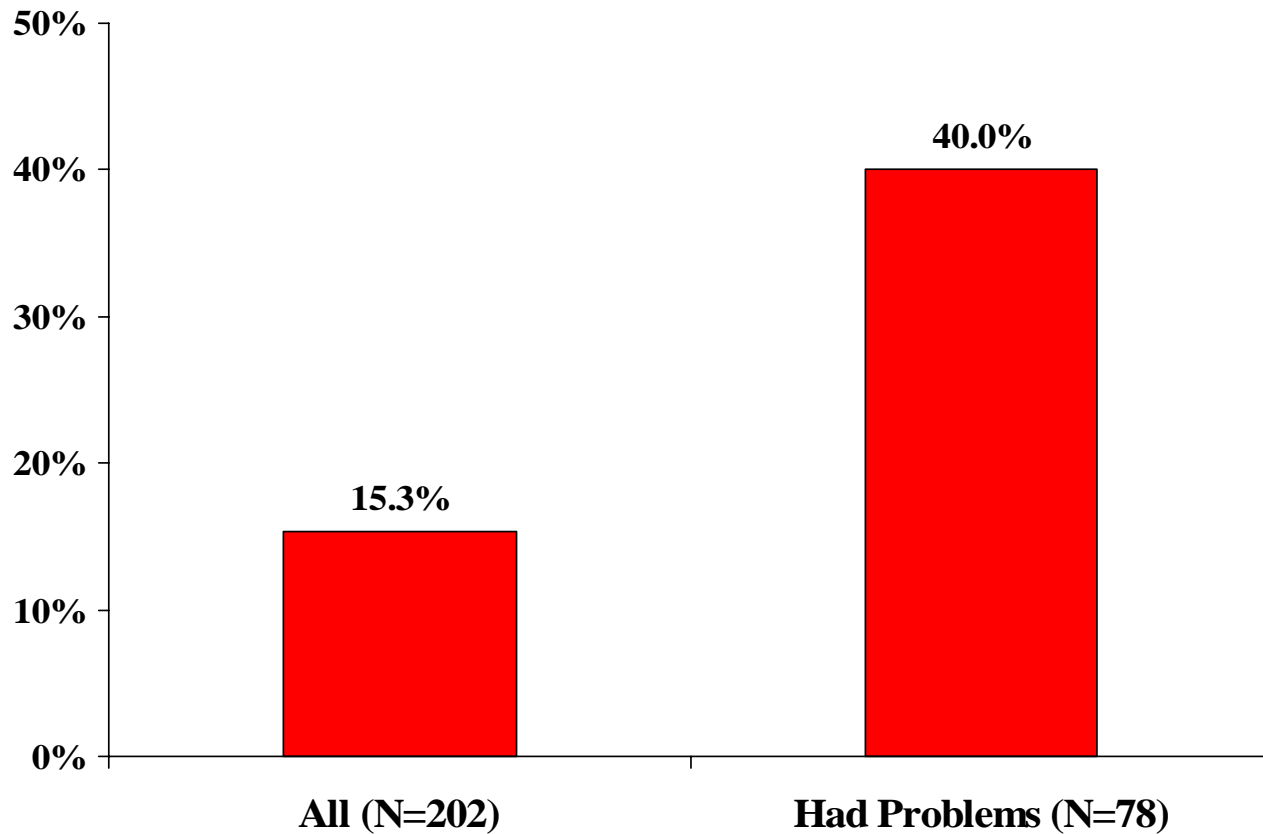


A year ago, where did the patient usually receive his/her infusions? Does he/she still get his/her infusions at the same location? Where does he/she get his/her infusions now? Base: Has changed infusion site N=35

\*Source: The Immune Deficiency Foundation 2005 telephone survey of Medicare Patients.



# Negative Health Effects as a Result of Problems Getting IVIG



Q14c. Have these problems getting IVIG in the past 12 months had any negative effects on your health?



# IDF Action Alert

## On-line Advocacy Program

### *IDF Action Alert*

Ensure Access to IVIG  
for Medicare Patients  
Please tell your story  
to Congress.



*Activity Sept. 1, 2005 – December 31, 2006*

Total Messages	Total Activists
4,447	1,260



## Capitol Hill Day 2006

- 65 people attended
- A total of 144 meetings took place
- Reached 110 Members of Congress





## IDF Strategies 2006

- Partnership with American Academy of Allergy, Asthma and Immunology (AAAAI)
  - IDF held a roundtable on IVIG reimbursement at AAAAI's annual conference, March 2006
  - Joint IDF/AAAAI Specialist Physician Perspectives on Primary Immune Deficiency Survey
  - Development of a Tool Kit for physicians to use with local carriers for denials of IVIG claims
  - Working with AAAAI to reimburse IVIG as a Biologic Response Modifier



## Anecdotal and Quantifiable Data

- Patient calls (de-identified) and visits shared with Congress, CMS, FDA, Industry
- IDF Surveys: the only quantifiable data on the IVIG reimbursement crisis is what is critical



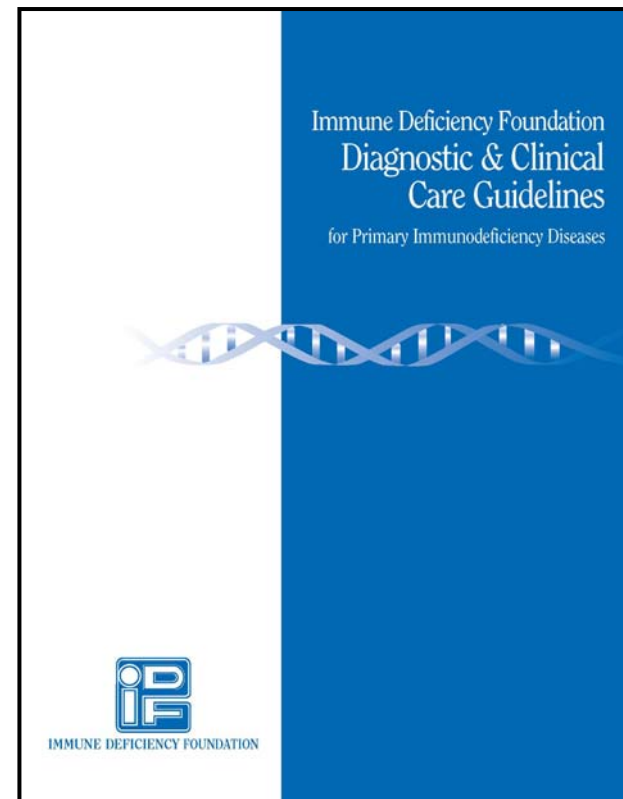
# Medical Programs



# Diagnostic and Clinical Care Guidelines

New in 2006!

Resource for  
patients and  
healthcare  
professionals







# A Guide for Nurses on Immune Globulin Therapy

Revising in 2007  
with IDF's Nursing  
Advisory Committee

A GUIDE FOR NURSES



on Immune Globulin Therapy

Prepared by  
The Immune Deficiency Foundation  
Nursing Advisory Committee



## Visiting Professor Program

- Provides faculty with a Visiting Professor with expertise in primary immune deficiency diseases
- Visiting Professors available to teaching hospitals throughout North America
- Expert clinical immunologists to lead grand rounds and other educational activities



## Consulting Immunologist Program

- Gives patients the benefit of a second medical opinion on primary immune deficiency diseases from a national network of renowned immunologists
- Free physician to physician consults
- Consults or second opinions on issues of diagnosis, treatment and disease management
- Access to faculty of recognized leaders in clinical immunology

# US Immunodeficiency Network





## Mission

- Fund peer reviewed research grants for primary immune deficiency diseases
- Establish a multi-faceted mentoring program to introduce new investigators into the field and stimulate interest in research
- Establish a Repository for banking DNA and cell lines from patients
- Redesign and expand the Immunodeficiency Patient Registries



Thank You!