



Immune Deficiency Foundation

Presentation to

IPOPI

October 6, 2006



Creation of IPOPI

The IDF Helps Make History at Oxford

Delegates Attending International Meeting of Patient Support Organizations



Front Row, from left to right: Tuuja Zilliacus - Finland, Suzanne Hansen - Denmark, Jane Tiernan, Secretary - United Kingdom, Liz Beek - United Kingdom, Marcia Boyle - United States, Anne Gatehouse - France, Koruga Dragana - Yugoslavia, Joanna Zamszka - Poland

Back Row, from left to right: Ann Wikman - Sweden, Engelbert Schroll - Germany, Inger-Britt Ziener - Norway, Louise Carroll - New Zealand, Eva Brox (partially obscured) - Norway, Martin Gatehouse - France, Maj-Lis Hellstrom - Sweden, Bob LeBien - United States, Alan Scott - United Kingdom, Erica Post - Holland



Mission

- The national patient organization dedicated to improving the diagnosis and treatment of primary immune deficiency diseases through research, education and advocacy.
- Founded in 1980





Start Up Funding

- A lot of volunteer commitment!
- Credibility: Have a mission, organizational structure and plan in place
- American Legion Child Welfare Foundation
- Ongoing Support: Defined goals and successes



IDF's Long Term Strategic Goals National in Scope

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



Immune Deficiency Foundation

- ❖ Board of Trustees
- ❖ Medical Advisory Committee
- ❖ Volunteer Network
- ❖ Professional Staff

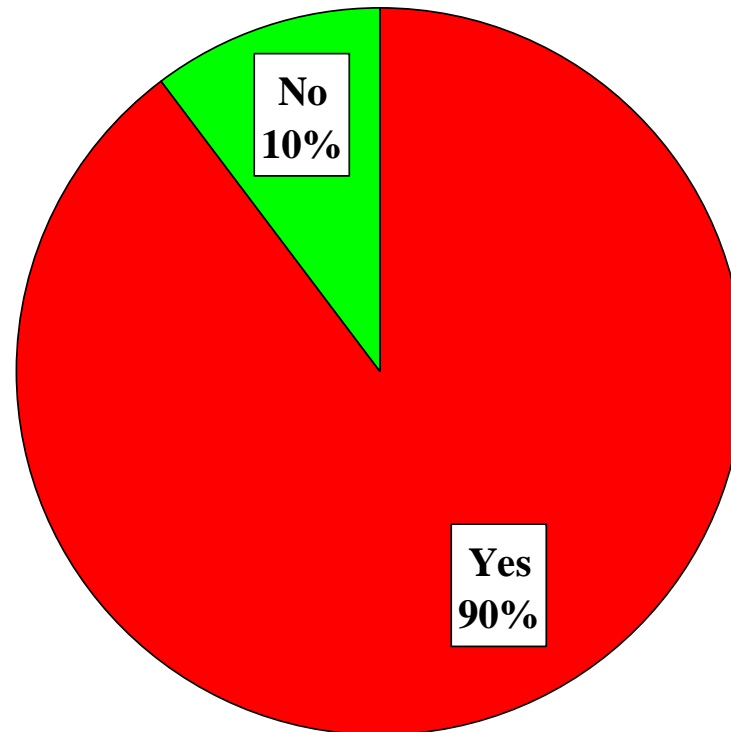


IDF Survey of Patients using IVIG: 1997

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



Repeated or Unusual Infections Prior to Diagnosis

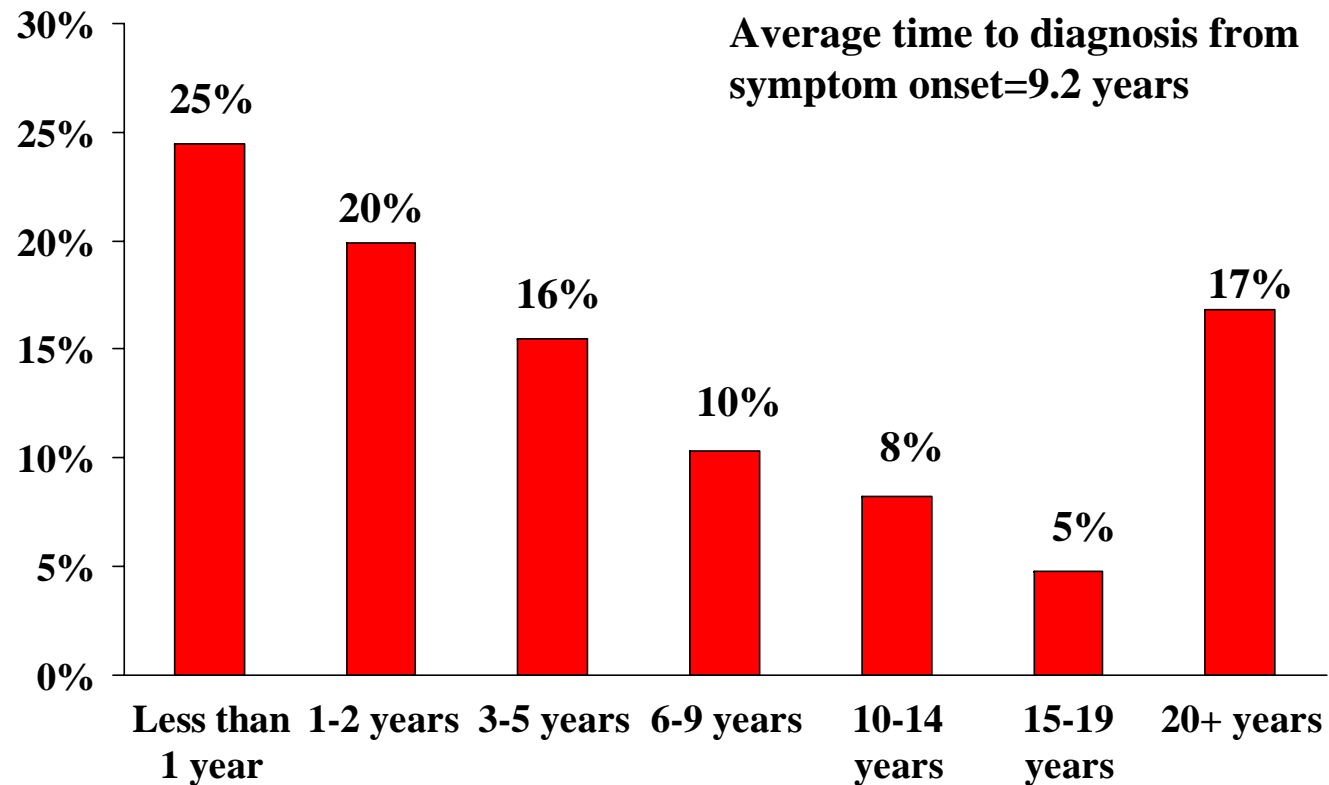


Q3. Did the patient exhibit repeated or unusual infections prior to diagnosis as immune deficient?

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)



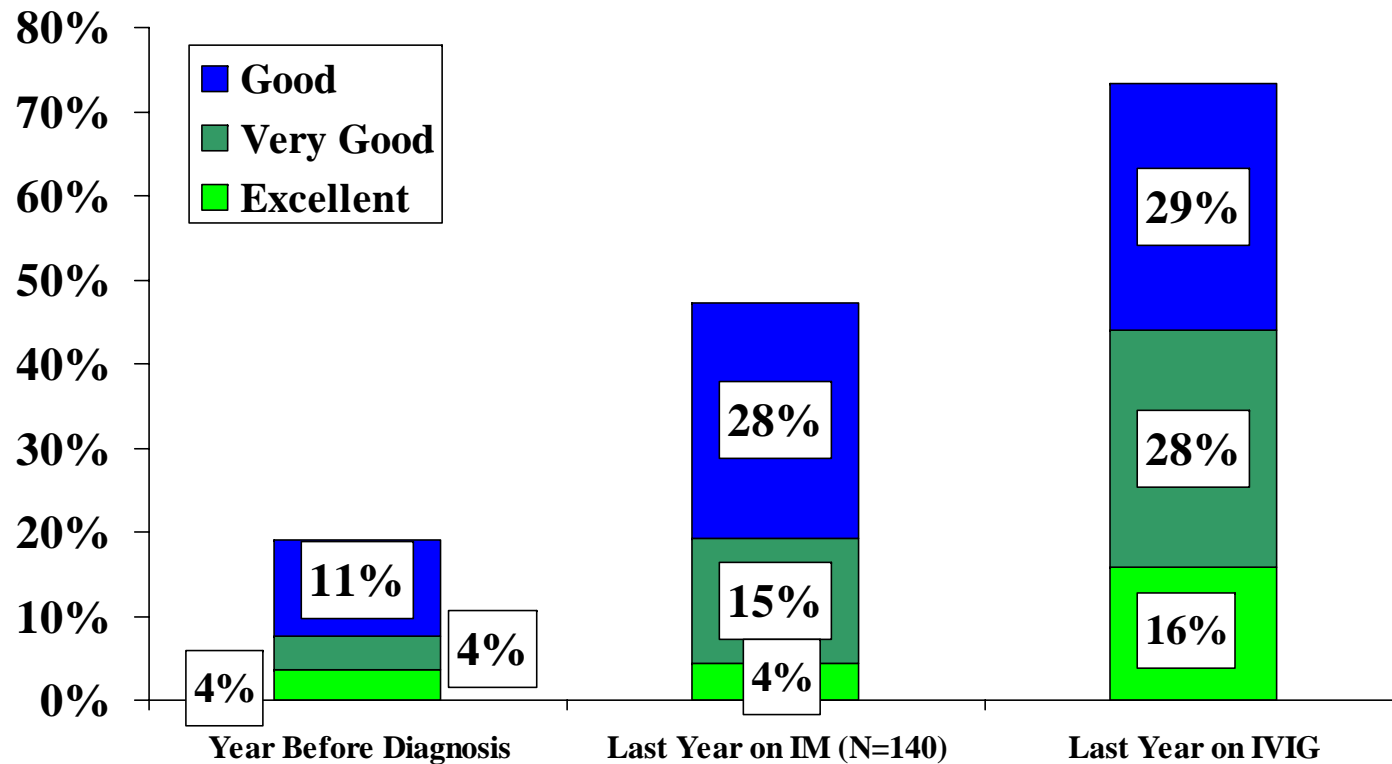
Permanent Functional Impairment Prior to Diagnosis



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



Family Retreats



Set Sail for a
Healthier Life!

Wintergreen, Virginia
June 9-11

Colorado Springs, Colorado
November 17-19



Nationwide Patient Education Meetings

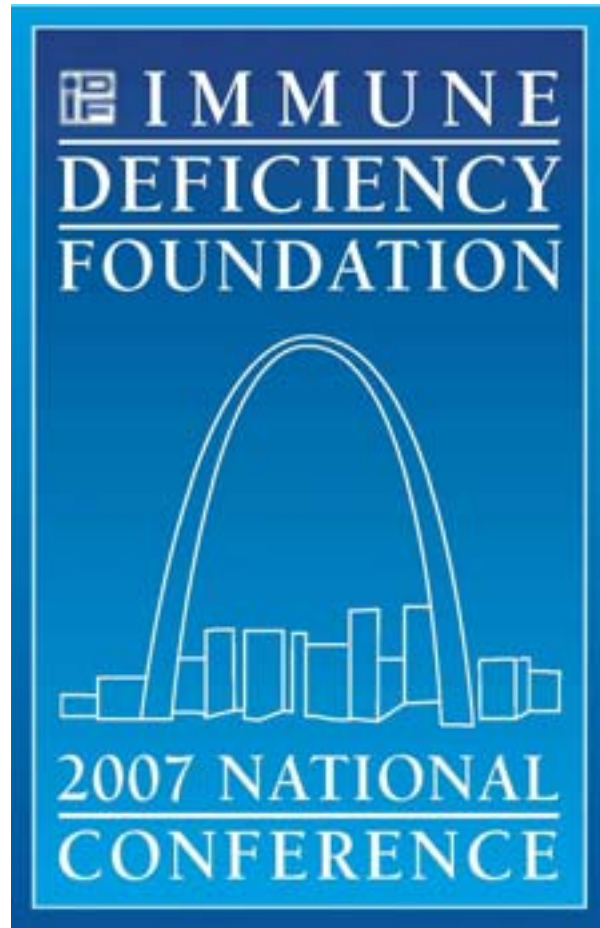
Volunteer and Staff
Organized

Up to 150 attendees per
meeting





2007 IDF National Conference



St. Louis, Missouri

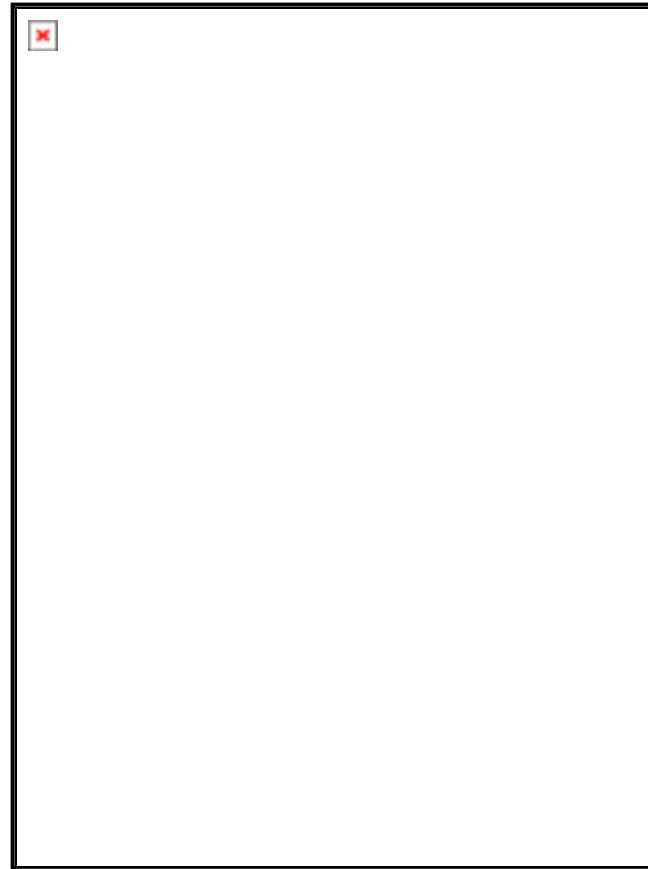
Renaissance Grand Hotel

June 28-30, 2007



Patient and Family Handbook

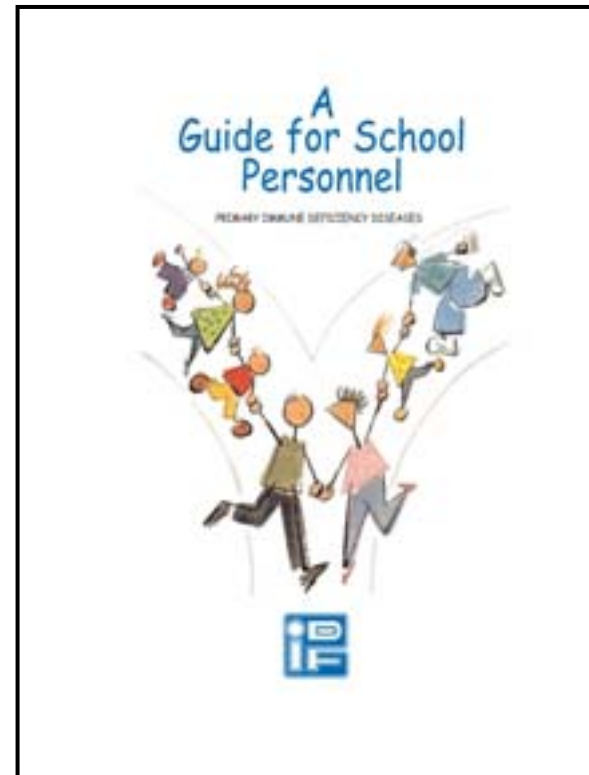
- Under revision, to be unveiled at the 2007 National Conference in St. Louis





A Guide for School Personnel

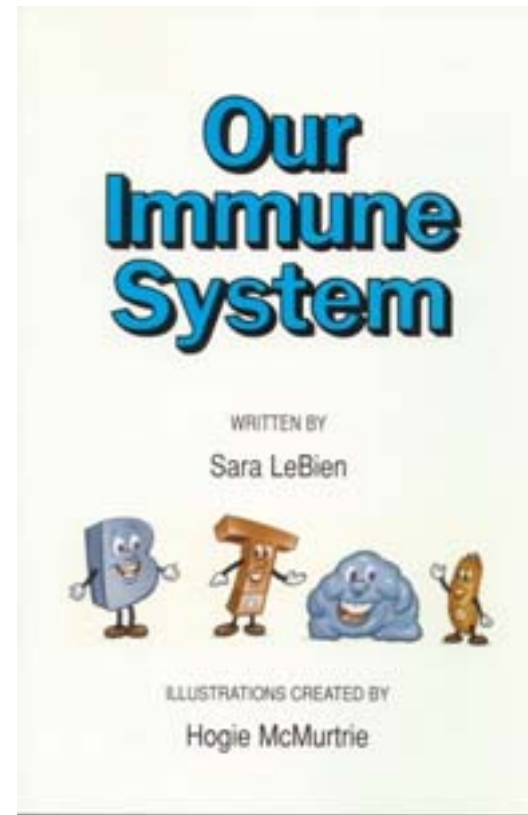
New in 2005!





Patient Publications

Our
Immune
System





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



Communications



www.primaryimmune.org

Monthly IDF Web Site Activity

	Hits Entire Site	Hits Ave Per Day	Unique Visitors	Visitors More Than Once
Monthly Average	967,5000	33,000	19,000	44,000

- Secure on-line donations



The IDF Advocate Newsletter

- Circulation over 20,000
- Published 3 times a year
- Donation envelope in every newsletter and patient packet





Patient Advocacy And Public Policy



IDF is the first place to turn for
help for patients and families



Types of Issues Addressed

	January 1 – July 31, 2006	
	Calls & E-mails combined	
	<i>Number</i>	<i>Percentage</i>
Education (questions related to primary immune deficiency, newly diagnosed, literature requests)	1217	38%
Physician Location/CIP Referral	366	12%
Insurance/Financial Assistance	498	16%
IGIV Access	530	17%
Diagnosis (looking for)	90	3%
*Other	339	11%
Treatment	140	4%
TOTAL	3180	100%
AVERAGE per MONTH	454	

**Issues include: Employment discrimination, volunteer opportunities, unrelated diagnoses and peer support*



Patients have suffered serious issues of access to IGIV as a result of Medicare reimbursement reductions.

- Since January 1, 2005 patient organizations have 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



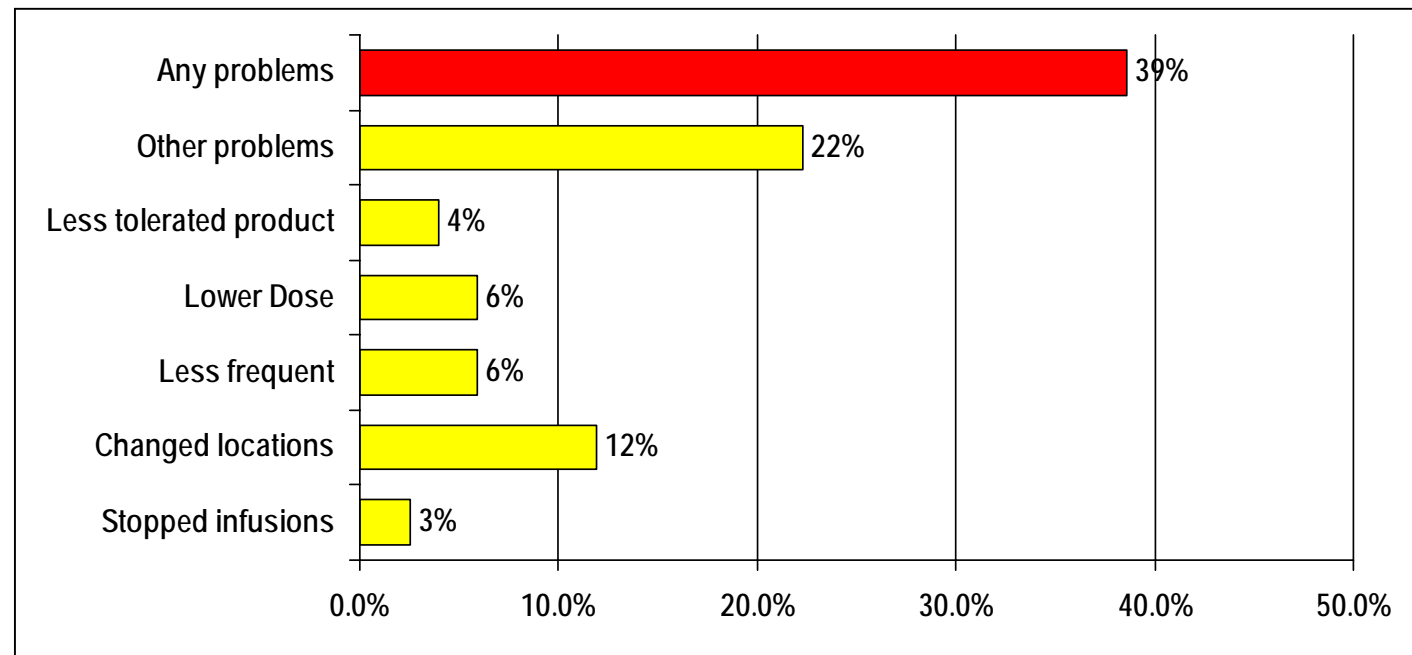
IDF Strategies 2005

- In 2005 IDF conducted 2 surveys to quantify the impact of reimbursement reductions.
 - Physician Survey – May 05
 - Patient Survey – May/July 05



Inadequate reimbursement is adversely affecting IVIG users

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

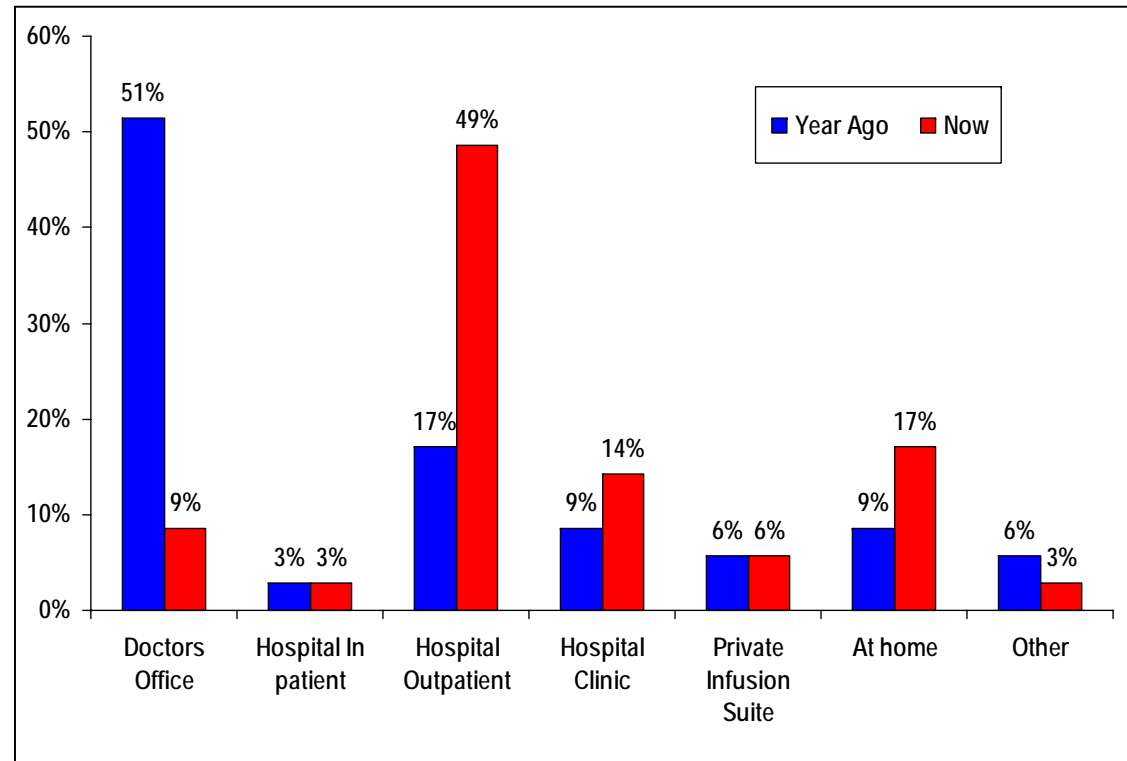


- Of the patients experiencing problems getting IVIG in the past 12 months, 40% say their health has been negatively affected.

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



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

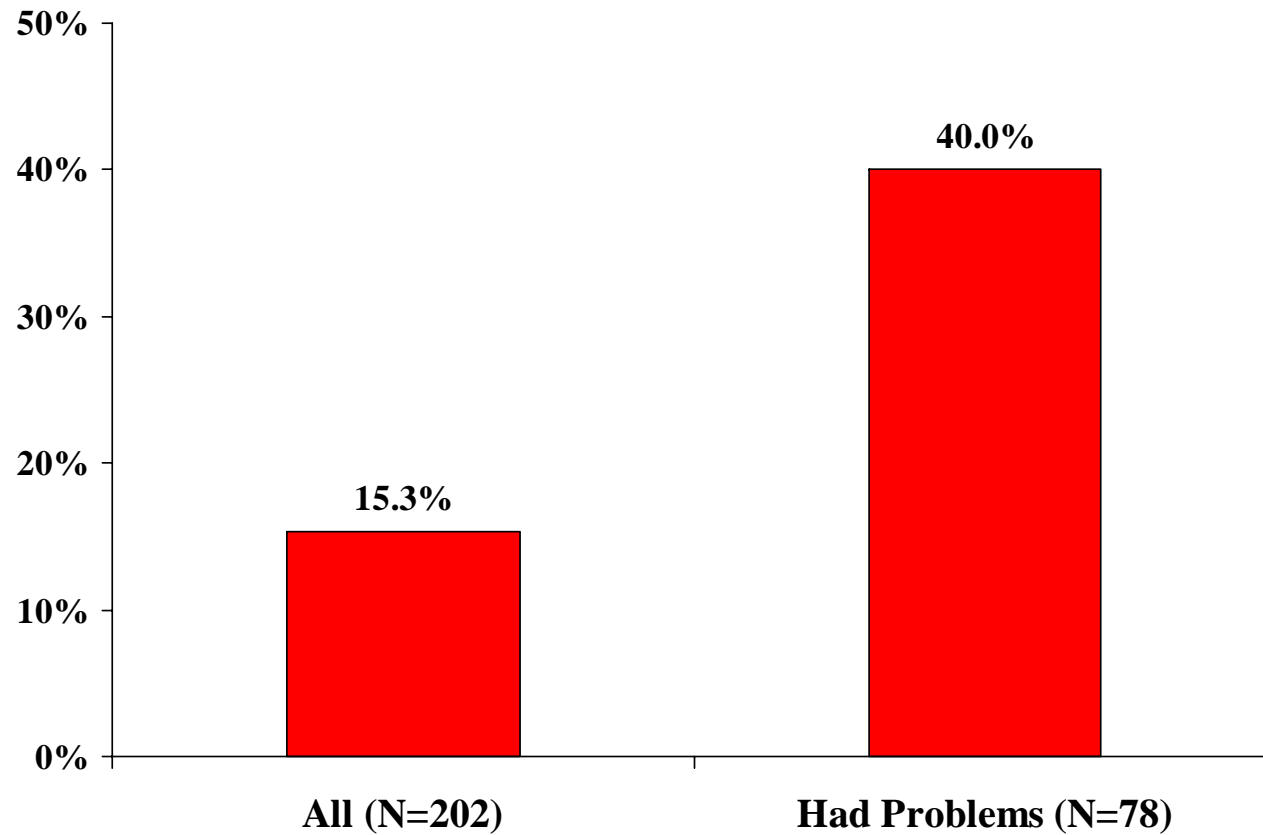


A year ago, where did the patient usually receive his/her infusions? Does he/she still get his/her infusions at the same location? Where does he/she get his/her infusions now? Base: Has changed infusion site N=35

*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 – July 31, 2006

Total Messages	Total Activists
4075	1185



Capitol Hill Day 2006

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





IDF Strategies 2006

- Partnership with 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/JCAAI to reimburse IVIG as a Biologic Response Modifier under the chemotherapy administration code, which would increase reimbursement by approximately 20%



Primary Immune Deficiency IVIG Group

- Primary Immune Deficiency Coalition: IDF is working jointly with the Jeffrey Modell Foundation, American Academy of Allergy Asthma & Immunology (AAAAI), and other PIDD medical societies with one voice on the issues of reimbursement and access to IVIG.



IDF Surveys

Access and Utilization Survey

- Mail patient survey, IDF
- Web-based physician survey, AAAAI
- Telephone survey of pharmacists, survey research firm



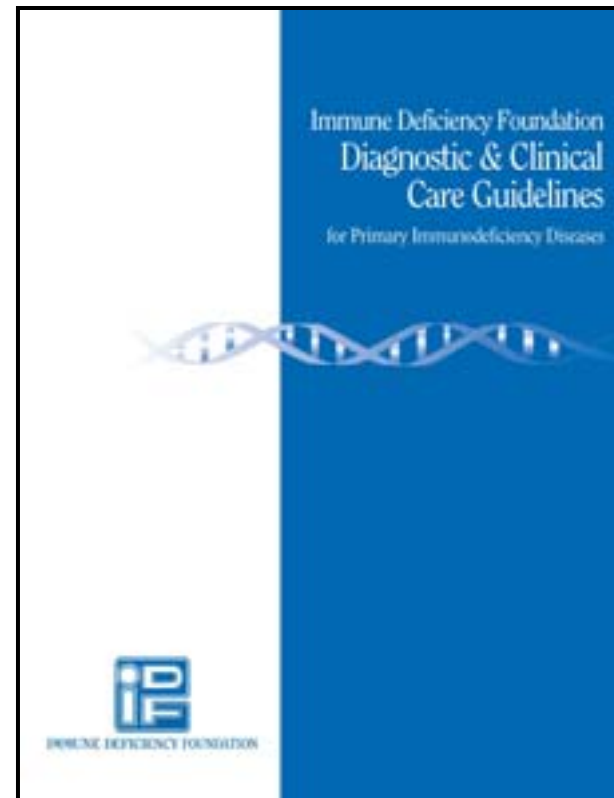
Medical Programs



Diagnostic and Clinical Care Guidelines

New in 2006!

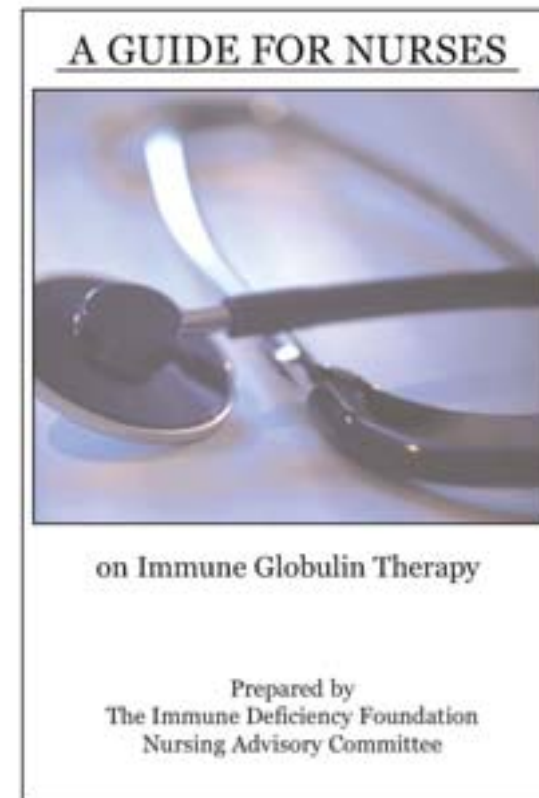
Resource for
patients and
healthcare
professionals





A Guide for Nurses on Immune Globulin Therapy

- Reprint in 2006
- Revising in 2007





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 (PIDD)
- 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 PIDD patients
- Redesign and expand the Immunodeficiency Patient Registries



Fund Raising



Funding Sources

- Corporate
 - Industries that produce products and services used by our community
 - Corporations with a history of philanthropy
 - Project specific and unrestricted
 - Recognition is important!



Funding Sources

- Individuals
 - patients
 - families
 - friends
 - public
 - medical professionals



Fund Raising Sources

- Foundations
 - International
 - National
 - Local
- Government
 - National
 - State or Regional
 - Local



Types of Fund Raising

- Individual Gifts – Tax advantages for giving
 - Mail, telephone or on-line
 - In memory of or In honor of
 - Major gifts
 - Planned giving
 - Gifts of securities
 - Gifts in kind
 - Pledges
 - Work place giving
 - Matching gifts



Types of Fund Raising

- Annual appeal
 - Send letters to mailing list
 - Post information on Web-site
 - Print article in newsletter



Types of Fund Raising

- On-line Philanthropy
 - On-line shopping generates donations
 - Percentage of each purchase is donated to favorite cause
 - Example of participating sites:
 - Better to Give
 - iGive.com



Types of Fund Raising

- Special Events
 - Nationwide groups host Blue Jeans for Healthy Genes
 - Wear jeans to raise funds





Blue Jeans for Healthy Genes

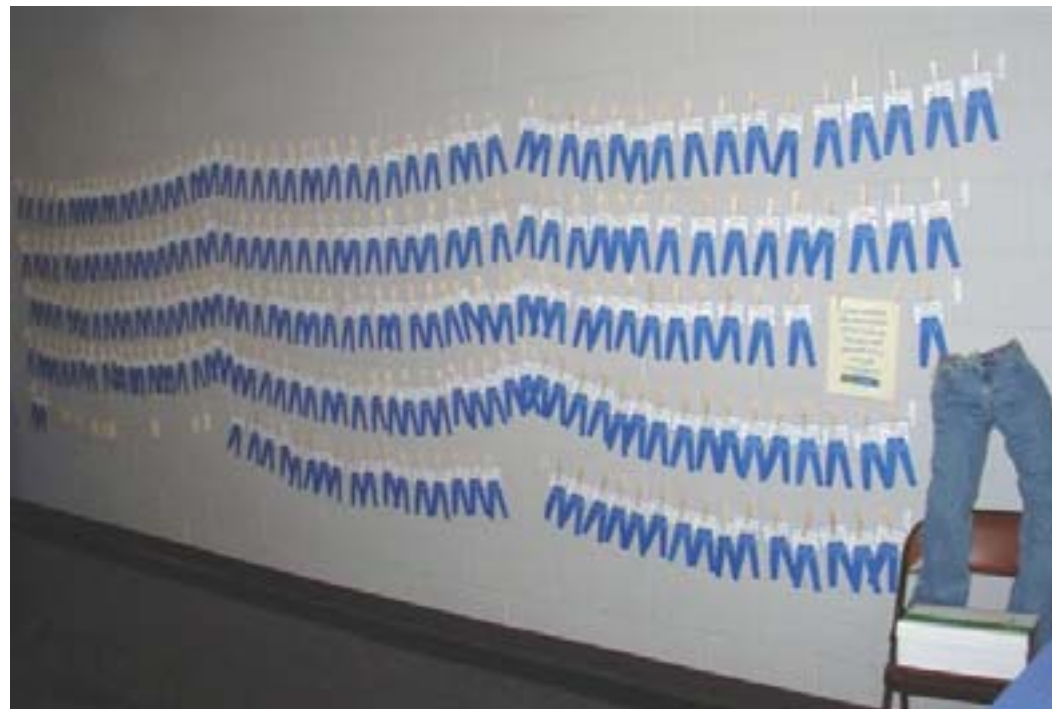
- Involve Children
 - Educational fund raising





Blue Jeans for Healthy Genes

- Involve Adults
 - Hanging up Jeans





Local Fundraising Examples

- New York Ski-a-thon - New York
- Wine Tasting - Connecticut
- Marathon Run - Florida
- Blood Drive - Ohio
- Crop for a Cure - North Carolina



Types of Fund Raising

- Fee for service
 - Charge for publication
 - Membership dues
 - Activity fees



Don't be afraid to ask
and give someone an
opportunity to make a
difference!