



2014 IDF Insurance Survey

This survey will focus on health insurance issues as experienced by persons with primary immunodeficiency disease (PI) and is funded completely by the Immune Deficiency Foundation (IDF).

The ultimate goal of the project is to help IDF better understand the different ways healthcare reform and health insurance may impact the PI population in the United States. The results from this survey will be used to create a manuscript for publication in peer reviewed journals and will also be used to help inform and educate policy makers.

At the end of the insurance survey you will also be asked seven questions on "biosimilars." The entire survey should, depending on your answers, take approximately 20-25 minutes to complete.

We do our best to keep your information confidential. Survey data is obtained and transmitted through a secure and encrypted process. All of your answers are grouped with all of the other answers, with none of your personal identifying information reported or used in the reporting.

You may refuse to answer questions, or discontinue the survey at any time with no penalty or loss of benefits you or your family receive from IDF. There is no benefit, in money, goods or services for anyone who decides to participate in this survey.

If you have any questions or concerns about this research, or your rights as a survey participant, please contact Christopher Scalchunes, Director of Survey Research at IDF. He can be reached at: 1.800.296.4433.

ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "agree" button below indicates that:

- you have read the above information
- you voluntarily agree to participate
- you are at least 18 years of age (you must be at least 19 years of age if you live in Alabama or Nebraska)

If you do not wish to participate in this survey, please decline participation by clicking on the "Disagree" button.

Agree

Disagree



2014 IDF Insurance Survey

S1 Are you a person with a primary immunodeficiency disease (PI) or parent/caregiver of a child **in the household with PI?**

- Person with PI 1g3-AR3y:g9AR31 -R639/U3-HR61
- Parent/caregiver
- Both
- Neither 1ARK16/9?AO 1



2014 IDF Insurance Survey

IF YOU ARE A PERSON WITH PI, PLEASE ANSWER SURVEY QUESTIONS ABOUT YOURSELF.

IF YOU DO NOT HAVE A PI, PLEASE ANSWER SURVEY QUESTIONS ABOUT THE OLDEST CHILD WITH PI IN HOUSEHOLD.

FOR THE REMAINDER OF THE SURVEY, WE WILL REFER TO THIS PERSON AS "THE PERSON," "THIS PERSON" OR "PERSON WITH PI."



2014 IDF Insurance Survey

3. What is the date of birth of the person in the household with a primary immunodeficiency disease (PI)?

Date of Birth: / /

4. What is the gender of the person?

- Male
- Female
- Other
- Refused

5. What is the person's specific PI diagnosis?

Please select only one.

- Agammaglobulinemia
- Ataxia Telangiectasia
- Chronic Granulomatous Disease
- Common Variable Immunodeficiency
- Combined Immunodeficiency
- Complement Deficiency
- DiGeorge Anomaly
- Hereditary Angiodema
- Hyper IgE Syndrome
- Hyper IgM Syndrome
- Hypogammaglobulinemia
- IgG Subclass Deficiency
- Selective IgA Deficiency
- Severe Combined Immunodeficiency
- Severe Congenital Neutropenia
- Specific Antibody Deficiency
- Wiskott-Aldrich Syndrome
- Not Sure/ Do not know
- Other

Other (please specify)



2014 IDF Insurance Survey

6. How old was the person when they were diagnosed with a PI?



2014 IDF Insurance Survey

7. Does the person with PI in your household currently have health insurance?

Yes

No



2014 IDF Insurance Survey

8. Why doesn't this person have health insurance?

- Cannot find a policy that covers the patient
- The policies the patient can have are too expensive
- The patient does not need health insurance
- Patient chooses not to have health insurance
- I prefer not to answer
- Had insurance but lost it
- Other reasons apply that are not listed
- Do not know/Not sure

Other (please specify)

9. How long has this person been without health insurance?

- Three months or less
- Four to 11 months
- One to two years
- More than two years
- Don't know/Not sure



2014 IDF Insurance Survey

10. What is the primary source of health insurance the patient is covered under?

- Employment based: Individual only
- Employment based: Employee-plus one
- Employment based: Family
- Purchased directly from an insurance company
- Government Health Insurance
- Over 65 & Retired
- Over 65 & Working
- Don't know/Not sure

11. What is this person's main type of health insurance?

- Employer sponsored group plan
- COBRA plan
- Individual policy plan (for individuals or family)
- Medicare plan
- Medicare Supplemental Plan
- Medicare Advantage Plan
- Medicare eligibility due to disability
- Medicaid
- State Children's Health Insurance Plan
- Exchange/Marketplace (State)
- Exchange/Marketplace (Federal)
- TRICARE
- Veterans Policy
- Not sure
- Other Insurance

Other (please specify)



2014 IDF Insurance Survey

12. What kind/level of State Exchange/Marketplace Health Insurance does the person have?

- Platinum
- Gold
- Silver
- Bronze
- Catastrophic
- Don't know/Not sure



2014 IDF Insurance Survey

13. What kind/level of Federal Exchange/Marketplace Health insurance does the person have?

- Platinum
- Gold
- Silver
- Bronze
- Catastrophic
- Don't know/Not sure



2014 IDF Insurance Survey

The next few questions ask about your awareness of a part of the Affordable Care Act that deals with prescription drug coverage.

14. Are you aware that if a plan is offered through the Health Insurance Marketplace ("Exchanges") the plan must cover at least one drug in every category and class?

Yes

No

15. Are you aware that if a plan is offered through the Health Insurance Marketplace ("Exchanges") it must contain the same number of drugs in each category and class as your state's health insurance benchmark plan?

Yes

No

16. Are you aware that if a plan is offered through the Health Insurance Marketplace ("Exchanges") that you "have access to clinically appropriate drugs that are prescribed by a provider but are not included on the plan's drug list"?

Yes

No



2014 IDF Insurance Survey

17. Think back to what kind of health insurance the person with PI had in September of 2013 and select the proper choice below.

- Employer sponsored group plan
- COBRA plan
- Individual policy plan
- Medicare plan
- Medicare Supplemental Plan
- Medicare Advantage Plan
- Medicare eligibility due to disability
- Medicaid
- SCHIP or other government policy
- TRICARE
- Veterans Policy
- No health insurance
- Don't know/Not sure
- Other

Other (please specify)



2014 IDF Insurance Survey

18. Please rate your satisfaction with the person's current health insurance coverage.

- Very satisfied
- Somewhat satisfied
- Unsure
- Dissatisfied
- Very Dissatisfied



2014 IDF Insurance Survey

19. Do you know how much you pay for your health insurance premium each month?

- Yes
- No
- Don't have a health insurance premium
- Don't know/Not sure



2014 IDF Insurance Survey

20. Please tell us how much you pay for your health insurance premium(s) each month. If you are not sure, please use your best estimate.

Please use whole dollar amounts. For example, if it costs you \$250.25 per month, please enter 250



2014 IDF Insurance Survey

A deductible is the amount you owe for healthcare services your health insurance or plan covers before your health insurance or plan begins to pay.

For example, if your deductible is \$1,000, your PLAN won't pay anything until you've met your \$1,000 deductible for covered healthcare services. The deductible may not apply to all services.

21. Do you have different deductibles, one for your prescriptions and one for your other medical expenses?

- Yes
- No
- Not sure



2014 IDF Insurance Survey

22. Do you know how much your health insurance deductible is?

- Yes
- No
- Don't have a deductible
- Don't know/Not sure



2014 IDF Insurance Survey

23. Please tell us how much your total yearly deductible(s) are for your insurance plan(s).

Please use whole dollar amounts. For example, if it costs you \$250 per year, please enter 250

Please enter "0" if you have no deductible.



2014 IDF Insurance Survey

24. Does your insurance have a maximum out-of-pocket amount you must pay each year before your health insurance plan pays 100%?

- Yes
- No
- Don't know/Not sure



2014 IDF Insurance Survey

25. What is the maximum amount of your yearly, out-of-pocket expenses for healthcare?

Please use whole dollar amounts. For example, if it costs you \$5000.25 per YEAR, please enter 5000



2014 IDF Insurance Survey

26. If the person with PI were to get seriously ill, how confident would you be that the patient would ...

	Very confident	Somewhat confident	Not very confident	Not at all confident
Receive high quality and safe medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receive the most effective drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receive the best medical technology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be able to afford the care needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



2014 IDF Insurance Survey

27. In 2013, what problems, if any, did you have understanding the person's prescription medicine benefits for your health insurance?

	No problem	Minor problem	Moderate problem	Serious problem
Prior to signing up for health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After you signed up for health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28.

Currently, for your 2014 policy, how much of a problem is it, if at all, for you to understand the person's prescription medicine benefits for your health insurance?

	No problem	Minor problem	Moderate problem	Serious problem
Prior to signing up for health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After you signed up for health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



2014 IDF Insurance Survey

29. Does the person with PI have access to an immunologist who specializes in primary immunodeficiency?

Yes

No



2014 IDF Insurance Survey

30. Why doesn't this person have access to an immunologist who specializes in primary immunodeficiency?

- Can't find an immunologist who specializes in primary immunodeficiency
- The immunologist is too far away to be convenient
- The immunologist is no longer covered by health insurance
- Other

Other (please specify)



2014 IDF Insurance Survey

An “in-network provider” is one contracted with the health insurance company to provide services to plan members for specific pre-negotiated rates.

An “out-of-network provider” is not contracted with the health insurance plan. Usually, if you visit a physician or other provider out-of-network you would be responsible for paying more than if you see a provider who is “in-network”.

31. Is this immunologist “in-network” for this person’s health insurance purpose or “out of network” for their health insurance?

- In-network
- Out-of-network
- Don't know/Not sure



2014 IDF Insurance Survey

32. Do you have to pay more for this person to see this immunologist than the patient's other doctors?

- Yes
- No
- Don't know/Not sure



2014 IDF Insurance Survey

33. Approximately how far in miles does the person with PI have to travel, one way, to see the immunologist?



2014 IDF Insurance Survey

34. Since January 2014, please tell us about what kind of in-network and out-of-network challenges, if any, you have had with this person's health insurance.

If you have not had any of these problems, please move on to the next question.



2014 IDF Insurance Survey

35. Since January 2014, as a result of your health plan's rules, has the person with PI had any problems seeing any healthcare specialists?

Yes

No

36. Since January 2014, as a result of your health plan's costs sharing, has the person with PI had any problems affording visits to any healthcare specialists?

Yes

No



2014 IDF Insurance Survey

37. Since January 2014, how many emergency room visits (not overnight) has this person had?

38. Since January 2014, how many times were they hospitalized overnight or longer?



2014 IDF Insurance Survey

39. Does the person with PI take antibiotics routinely or daily as part of the treatment for the patient's primary immunodeficiency?

Yes

No



2014 IDF Insurance Survey

40. Approximately how many days since January 2014 have they used prescribed antibiotics?



2014 IDF Insurance Survey

41. Since January of 2014, how many infections, if any, did the person with PI have that required prescription antibiotics to help clear the infection?



2014 IDF Insurance Survey

42. Since January 2014, how many days, if any, was the person (or the parent/caregiver) unable to work or perform usual activities because of the patient's illness from PI?

If the patient is an infant/not applicable, please enter 999.



2014 IDF Insurance Survey

43. Overall, how would you rate your satisfaction with the quality of the healthcare the person with PI receives?

- Very satisfied
- Somewhat satisfied
- Neither satisfied, nor dissatisfied
- Dissatisfied
- Very dissatisfied



2014 IDF Insurance Survey

44. Since January 2014, was there any time when the person with Plid not fill, or refill a prescription because of out-of-pocket costs?

Yes

No



2014 IDF Insurance Survey

45. If yes, please tell us below which prescription drug(s) this person did not fill or refill.



2014 IDF Insurance Survey

46. Since January 2014, was there any time when the person with PI skipped a medical test because of out-of-pocket costs?

Yes

No



2014 IDF Insurance Survey

47. If yes, please tell us below which medical test(s) they skipped because of the cost.



2014 IDF Insurance Survey

48. Since January 2014, was there any time when the person with PI skipped a medical treatment recommended by a doctor because of out-of-pocket costs?

Yes

No



2014 IDF Insurance Survey

49. If yes, please tell us below which medical treatment(s) they skipped due to cost.



2014 IDF Insurance Survey

50. Since January 2014, was there any time when the person with P^{had} a medical problem but did not go to a doctor or medical clinic because of out-of-pocket costs?

Yes

No



2014 IDF Insurance Survey

51. If yes, please tell us below what medical problem(s) they had but did not go to a doctor due to the cost.



2014 IDF Insurance Survey

52. Since January 2014, was there any time when the person with P_{did} not see a specialist when the doctor recommended a referral to a specialist because of out-of-pocket costs?

Yes

No

53. If yes, please tell us below which specialist(s) they did not see due to cost.



2014 IDF Insurance Survey

54. Since January 2014, have you done any of the following in order to pay for the person's healthcare costs?

SELECT ALL THAT APPLY

- Spent less on entertainment
- Spent less on groceries
- Spent less on your family
- Used your credit card more often
- Postponed paying other bills
- Taken out a loan to pay for medical bills
- Applied for government assistance
- Other
- None of the above

Other (please specify)



2014 IDF Insurance Survey

55. Since January 2014, were there times the person (or parent/caregiver of the person) with PI had problems paying or was unable to pay for medical bills?

Yes

No



2014 IDF Insurance Survey

56. Since January 2014, have you had to declare bankruptcy due to the person's medical bills?

Yes

No



2014 IDF Insurance Survey

57. Has the person with PI EVER been treated with intravenous immunoglobulin (IVIG), subcutaneous immunoglobulin (SCIG) therapy or intramuscular (IM) immunoglobulin therapy for at least six (6) months?

Yes

No



2014 IDF Insurance Survey

58. Why has the person never been treated with immunoglobulin replacement therapy?

SELECT ALL THAT APPLY

- Never prescribed by the doctor
- Not medically indicated for the patient's disease
- Lack of insurance or inadequate insurance
- Denied treatment by insurance carrier
- Out-of-pocket cost
- Concerns about safety/side-effects
- Fear of treatment
- Other

Other (please specify)



2014 IDF Insurance Survey

59. Is the person currently being treated with intravenous immunoglobulin (IVIG), subcutaneous immunoglobulin (SCIG) therapy or intramuscular (IM) immunoglobulin therapy for his/her primary immunodeficiency disease?

- Yes, SCIG
- Yes, IVIG
- Yes, IM
- No



2014 IDF Insurance Survey

60. Why are they no longer being treated with immunoglobulin?

SELECT ALL THAT APPLY

- Immunoglobulin no longer prescribed by the doctor as medically necessary
- Safety/side effects
- Lack of insurance coverage/inadequate insurance
- Denied treatment by insurance carrier
- Too expensive (despite good insurance)
- Ig therapy not available
- Other

Other (please specify)



2014 IDF Insurance Survey

61. Does the person with PI prefer to receive immunoglobulin SCIG or IVIG?

- SCIG
- IVIG
- Does not matter
- Don't know/Not sure



2014 IDF Insurance Survey

62. Where does the person usually receive his/her Ig therapy?

- At home, self-infused
- At home, nurse infused
- Doctor's private office
- Hospital outpatient
- Hospital clinic
- Infusion suite
- Other

Other (please specify)



2014 IDF Insurance Survey

63. Approximately how long does it take to travel back and forth to the place where the person receives their Ig therapy?

	Hours	Minutes
Round-trip travel time:	<input type="text"/>	<input type="text"/>

64. _____

Not sure



2014 IDF Insurance Survey

65. Not including travel time, how long does each therapy session usually take?

	Hours	Minutes
Total time for therapy:	<input type="text"/>	<input type="text"/>

66. _____

Not sure



2014 IDF Insurance Survey

67. Is the person and/or their caregiver currently in school or employed?

Yes

No



2014 IDF Insurance Survey

68. Does the person (or the parent/caregiver of the person) need to take off from school or work to get their Ig therapy?

Yes

No



2014 IDF Insurance Survey

69. Since January 2014, how many total days, including half-days, has the person (parent/caregiver) needed to take off work or miss school to get their Ig therapy? If none, please enter "0" in the fields below.

Missed Days

Days missed
work

Days missed
school



2014 IDF Insurance Survey

70. Where would the person with PI prefer to receive Ig therapy?

- At home, self-infused
- At home, nurse infused
- Doctor's private office
- Hospital outpatient
- Hospital clinic
- Infusion suite
- Other

Other (please specify)



2014 IDF Insurance Survey

71. Who determines where they receive their Ig therapy?

- Person with PI/caregiver
- Doctor
- Medical facility
- Health Insurance provider
- Other

Other (please specify)



2014 IDF Insurance Survey

72. Who usually administers the Ig therapy?

- Doctor
- Nurse
- Person with PI (self-infused)
- Other family member
- Other

Other (please specify)



2014 IDF Insurance Survey

73. Which of the following Ig products does the person currently use?

- Bivigam (Biotest)
- Carimune (CSL Behring)
- Flebogamma (Grifols)
- Gammagard Liquid (Baxter)
- Gammagard S/D (Baxter)
- Gammaked (Kedrion)
- Gamunex-C (Grifols)
- Gammaplex (Bio Products)
- Hizentra (CSL Behring)
- HyQvia (Baxter)
- Octagam (Octapharma)
- Privigen (CSL Behring)
- Other
- Don't know/Not sure

Other (please specify)



2014 IDF Insurance Survey

74. Who was primarily responsible for the selection of the Ig product that the person uses?

- Person with PI/caregiver
- Doctor
- Medical facility
- Health Insurance provider
- Not sure
- Other

Other (please specify)



2014 IDF Insurance Survey

75. How often does the person receive the Ig product they prefer most?

- Always
- Most of the time
- Some of the time
- Only occasionally
- Never
- Only tried one product
- I do not know what product the patient prefers



2014 IDF Insurance Survey

76. On average, how often does the person with PI get their IVIG, SCIG or IM therapy?

- Daily
- Three times per week
- Two times per week
- Every week
- Every two weeks
- Every three weeks
- Every four weeks
- Every five weeks
- Every six weeks or more

77. About how many grams of Ig per infusion does they normally receive?

For SCIG if you do not know the number of mL but know the number of grams, please use grams.

For IVIG you would only need to enter the information in grams.

	Grams (IVIG)	mL (SCIG)
Amount of Ig infused:	<input type="text"/>	<input type="text"/>

78. _____

- Not sure

79. About how much does the person weigh in pounds?



2014 IDF Insurance Survey

80. How satisfied is the person with the ability of Ig therapy to control the severity or frequency of infections in the patient?

- Very satisfied
- Somewhat satisfied
- Unsure
- Dissatisfied
- Very Dissatisfied



2014 IDF Insurance Survey

81. Does the person's insurance plan cover both SCIG and IVIG?

- Yes
- No
- Don't know/Not sure



2014 IDF Insurance Survey

82. Do you know if the person's immunoglobulin prescription is covered under the health insurance plan's medical benefit or pharmacy benefit?

- Medical benefit
- Pharmacy benefit
- Don't know/not sure



2014 IDF Insurance Survey

83. Does the person's health insurance limit the amount of grams of immunoglobulin the patient receives, or does the patient receive the FULL amount of immunoglobulin prescribed by the doctor?

- The number of grams of immunoglobulin is limited by health insurance
- The number of grams of immunoglobulin is not limited by health insurance
- Don't know/ not sure



2014 IDF Insurance Survey

84. Since January 2014, has there been a time when the person skipped or delayed receiving their Ig therapy?

Yes

No



2014 IDF Insurance Survey

85. How many times since since January 2014 have they skipped or delayed receiving their Ig therapy?



2014 IDF Insurance Survey

86. What reason(s) did the person with PI have for skipping or delaying their Ig therapy?

SELECT ALL THAT APPLY

- Forgot about Ig therapy
- Did not want to be bothered by it
- Scheduling conflict
- Could not get off work/school
- Was too sick for Ig therapy
- My part of the cost of therapy was too expensive
- Had problems with health insurance company/coverage
- Person/caregiver did not feel the Ig therapy was needed
- Doctor did not feel the Ig therapy was needed
- The side effects were/are too great
- Too busy
- Could not get the Ig product wanted/normally receive
- Other

Other (please specify)

87. Using your answers above, what would you say is the main reason they skipped or delayed receiving their Ig therapy?

- Forgot about Ig therapy
- Did not want to be bothered by it
- Scheduling conflict
- Could not get off work/school
- Was too sick for Ig therapy
- My part of the cost of therapy was too expensive
- Had problems with health insurance company/coverage
- Person/caregiver did not feel the Ig therapy was needed
- Doctor did not feel the Ig therapy was needed
- The side effects were/are too great
- Too busy
- Could not get the Ig product wanted/normally receive
- Other



2014 IDF Insurance Survey

For the next question please keep in mind the following definitions:

CO-PAY: A co-pay means that you pay a specific amount of out-of-pocket expense for healthcare services at the time the service is provided. Co-pays are typically not expensive, for example they may require you to pay \$25 for a doctor visit or \$10 per prescription.

COINSURANCE: Coinsurance means you pay a percentage of the costs of your healthcare. For example, if you have an 80/20 coinsurance rate, your insurance plan pays 80% of your medical expenses, and you are responsible for the remaining 20% of your medical expenses.

88. Do you currently have a co-pay for the Ig therapy, or do you have coinsurance for the Ig therapy?

- Co-pay for Ig therapy
- Coinsurance for Ig therapy
- I don't have any co-pays or coinsurance for Ig therapy
- Don't know/not sure



2014 IDF Insurance Survey

89. How much is your monthly co-pay for Ig therapy treatment?

Please use whole dollar amounts. For example, if it costs you \$100.25 per co-pay, please enter 100

90. _____

Don't know/Not sure



2014 IDF Insurance Survey

91. Since September 2013, what changes, if any, have you experienced in the amount of the co-pays for the Ig therapy?

- I pay MORE for my co-pays
- I pay LESS for my co-pays
- There have been no changes in my co-pays
- Don't know/not sure



2014 IDF Insurance Survey

92. Since September of 2013, has the person's health insurance coverage switched from a co-pay for the Ig therapy to co-insurance for the Ig therapy?

- Yes
- No
- Don't know/Not sure



2014 IDF Insurance Survey

93. What is the percentage you must pay in coinsurance for the Ig therapy?

- 10%
- 15%
- 20%
- 25%
- 30%
- 40%
- 50%
- Other

Other (please specify)



2014 IDF Insurance Survey

94. How much do you have to pay for the person's coinsurance for each month of Ig therapy treatment?

Please use whole dollar amounts. For example, if it costs you \$100.25 per month, please enter 100

95. _____

Don't know/Not sure



2014 IDF Insurance Survey

96. Since January of 2014, what changes, if any, have you experienced in the percent of coinsurance you have to pay?

- I pay a HIGHER PERCENT for my coinsurance
- I pay a LOWER PERCENT for my coinsurance
- There have been no changes in my coinsurance
- Not sure/Don't know



2014 IDF Insurance Survey

The next few questions are going to ask you about types of financial assistance that you may receive to help pay for the costs of Ig therapy.

It is possible for someone to receive financial assistance in different ways.

From:

1. A foundation or other non-profit organization that gives money to patients for co-pay/coinsurance, or premium assistance.
2. A manufacturer of Ig therapy.
3. A home healthcare company or specialty pharmacy- a company that provides Ig therapy product and sometimes nursing services to patients in their home may provide a payment plan or have a compassionate care program for patients.
4. Physician's Office or Infusion Center- may have a payment plan or compassionate care program for patients.

97. Is the person with PI currently receiving any financial assistance for co-pay, co-insurance or health insurance premium expenses?

- Yes
- No



2014 IDF Insurance Survey

98. What type of organization gives the person assistance and what type of payment do they help with?

SELECT ALL THAT APPLY

	Foundation	Manufacturer	Hospital System	Specialty Pharmacy	Home Healthcare
Co-pay	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coinsurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Premium assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

99.

Since January 2014, please tell us how much total assistance the person received for the following.

Please use whole dollar amounts. For example, if you receive \$250.25, please enter 250

Co-pay assistance:

Co-insurance assistance:

Premium assistance:



2014 IDF Insurance Survey

100. Since January 2014, due to health plan rules, has the person ever had a problem in getting his/her regular infusion?

Yes

No



2014 IDF Insurance Survey

101. Since January 2014, which of the following events, if any, has the person experienced due to health plan rules?

- Site of care for infusion changed
- Increased interval between infusion
- Reduced dosage of infusion
- Denied Ig therapy treatment
- Delayed infusions
- Cancelled infusions
- Switched to less tolerated product
- Switched to less preferred product
- Switched from IVIG to SCIG
- Switched from SCIG to IVIG
- No product available
- Reimbursement problems
- Treating physicians now out of network
- Other problem

Other (please specify)

102. Since January 2014, how many times have they experienced a problem getting their regular infusion?



2014 IDF Insurance Survey

103. Since January 2014, has there been a change in the person's access to medicines and in your opinion, why?

Please use the text box below to share your thoughts with us. If there have been no changes, please continue to the next page.



2014 IDF Insurance Survey

104. Since January 2014, has there been a change in the person's access to healthcare providers and in your opinion, why?

Please use the text box below to share your thoughts with us. If there have been no changes, please continue to the next page.



2014 IDF Insurance Survey

105. Do you have any other comments about your experiences with health insurance or health insurance reform that you would like to share with us?

If so, please use the text box below.



2014 IDF Insurance Survey

106. What state do you live in?

107. Please enter your five digit zip code below.

108. Which of the following categories would best describe the race or ethnicity of the person with PI?

- American Indian/Alaskan native
- Asian/Pacific Islander
- Black/African-American
- Hispanic or Latino
- White, non-Hispanic
- Two or more races
- Other

Other (please specify)

109. What is the current employment status of the person (head of household if patient is a child)?

- Employed full time
- Employed part time
- Unemployed, looking for work
- Student
- Homemaker
- Disabled/too ill to work
- Retired
- Other

Other (please specify)

110. What is the last grade or year of school completed by the person (head of household if patient is a child)?

- 8th grade or less
- Some high school
- High school grad/GED
- 1-3 years of college
- 4 year college graduate
- Graduate or professional degree

111. What was the person's total household income last year?

- 0 to \$24,999
- \$25,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,000
- \$100,000 to \$149,999
- \$150,000 or more



2014 IDF Insurance Survey

THE NEXT FEW QUESTIONS ARE ABOUT A TOPIC THAT IS NEW TO OUR COMMUNITY.

IDF is interested in learning what is important to you as a person who uses a biologic drug such as immunoglobulin.

As part of the Affordable Care Act, Congress mandated that the FDA develop a pathway for the development of new biologic drugs that are similar but not identical to an FDA-approved biologic drug, called a reference drug.

The new law is intended to make the market for biological products more competitive and possibly less costly. These new drugs are called biosimilars; they are used for the same conditions like primary immunodeficiencies and are supposed to work like the reference drug but do not have a chemical structure identical to the reference drug.

112. *How drugs are approved*

How familiar are you with how the Food and Drug Administration (FDA) decides whether biological products can be marketed or not ?

- Very familiar
- Somewhat familiar
- Neither familiar nor unfamiliar
- Unfamiliar
- Very unfamiliar

Developing Biosimilar Products

Before approval of a biosimilar drug, the FDA is deciding whether or not to allow the use of clinical information learned through testing done by the original reference product with or without any additional clinical testing of the proposed biosimilar product.

Without clinical testing of a new biosimilar drug the steps for review and approval of biosimilar products would be faster than the process for approval of the reference product.

113. Should biosimilar products be subject to the same testing procedures as the reference drugs are?

- Yes
- No
- Don't know/Not sure

114. Why?

115.

In Europe, biosimilar products have been permitted since 2006. FDA accepted its first biosimilar applications this past summer (2014). The rules regarding FDA's requirement on interchangeability between the reference product and the biosimilar have not yet been finalized.

Should biosimilar drug applications be permitted to include the prior results of clinical testing using the reference drugs?

- Yes
- No
- Don't know/Not sure

116. Why?

117.

Naming Biosimilar Products

Some drugs have a brand name (such as Motrin or Advil) and a generic name (such as Ibuprofen) although they contain chemically identical active ingredients. Generic drug manufacturers market the drug using the same generic name as the company making the brand named drug.

However, a reference biological product and its biosimilar are similar but not completely identical.

Should a biosimilar drug have the same exact name as its reference drug?

- Yes
- No
- Don't Know/Not sure

118. Why?

119.

Switching from a Reference Drug to a Biosimilar

Should a pharmacist have the authority to substitute a biosimilar for its reference drug if it is deemed interchangeable by the FDA?

- Yes
- No
- Don't know/Not sure

120. Should the pharmacist be required to inform the patient before making such a switch

- Yes
- No
- Don't know/Not sure

121. Should the pharmacist be required to inform the patient's prescribing physician of the switch before making a switch?

- Yes
- No
- Don't know/Not sure

122. How likely would the patient be to switch to a less expensive, FDA approved biosimilar Ig therapy if that biosimilar was approved by their healthcare provider?

- Very likely
- Likely
- Neither likely nor unlikely
- Unlikely
- Very unlikely



2014 IDF Insurance Survey

That completes our survey!

Thank you for your time and participation!

If you have any questions or concerns about this project, please contact Christopher Scalchunes, Director of Survey Research at IDF. He can be reached at: 1.800.296.4433.