



2016 IDF Health 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.

It is possible that data obtained from this survey might be shared with other researchers or organizations conducting primary immunodeficiency research. In the event that this occurs, all personally identifying information will be removed in accordance with HIPPA regulations. The purpose of such data sharing is to aid future research on patients' health insurance experiences.

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 Tiffany Henderson, Survey Research Analyst at IDF. She 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)

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

Agree

Disagree **END SURVEY**



2016 IDF Health 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 **PATIENT INSTRUCTIONS**
- Parent/caregiver **PARENT INSTRUCTIONS**
- Both **PATIENT INSTRUCTIONS**
- Neither **END SURVEY**



2016 IDF Health Insurance Survey

PATIENT INSTRUCTIONS

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."

GO TO Q1a



2016 IDF Health Insurance Survey

PARENT INSTRUCTIONS

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."

GO TO Q1b

2016 IDF Health Insurance Survey

1a. We are going to start by asking some general questions about your health.

Please respond by marking one box per row.

	Excellent	Very Good	Good	Fair	Poor
In general, would you say your health is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, would you say your quality of life is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate your physical health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate your mental health, including your mood, and your ability to think?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

GO TO Q1



2016 IDF Health Insurance Survey

1b. We are going to start by asking some general questions about the health of your child with PI.

Please respond by marking one box per row.

	Excellent	Very Good	Good	Fair	Poor
In general, would you say their health is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, would you say their quality of life is:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate their physical health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, how would you rate their mental health, including their mood, and their ability to think?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

GO TO Q1



2016 IDF Health Insurance Survey

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

Date of Birth: MM / DD / YYYY

	/		/	
--	---	--	---	--

2. What is the gender of the person?

- Male
- Female
- Other
- Refused

4. 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 Angioedema
- 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)

--

GO TO Q5



2016 IDF Health Insurance Survey

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



(Less than one year old...99)

GO TO Q6a



2016 IDF Health Insurance Survey

6a Does the person with PI in your household currently have health insurance?

- Yes **GO TO Q7a**
- No **GO TO Q6b**

2016 IDF Health Insurance Survey

6b. 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
- Do not know/Not sure
- Other reasons apply that are not listed

Other (please specify)

6c. 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

GO TO Q_END_COMMENTS3



2016 IDF Health Insurance Survey

7a. 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

7b. 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) **GO TO Q7c**
- Exchange/Marketplace (Federal) **GO TO Q7d**
- TRICARE
- Veterans Policy
- Not sure
- Other Insurance

Other (please specify)

GO TO Q7e



2016 IDF Health Insurance Survey

7c. What kind/level of State Exchange/Marketplace Health Insurance does the person have?

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

GO TO Q7e



2016 IDF Health Insurance Survey

7d. What kind/level of Federal Exchange/Marketplace Health insurance does the person have?

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

GO TO Q7e



2016 IDF Health Insurance Survey

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

7e. 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

7f. 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

7g. 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

GO TO Q7new



2016 IDF Health Insurance Survey

7new. Please tell us the name of the Health Insurance Company that provides health insurance for the person with PI.

(i.e. - Aetna, Blue Cross, Cigna, United).

GO TO Q7h



2016 IDF Health Insurance Survey

7h. Think back to what kind of health insurance the person with PI had in September of 2015 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)

GO TO Q7i



2016 IDF Health Insurance Survey

7i. Please rate your satisfaction with the person's current health insurance coverage.

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

GO TO Q8



2016 IDF Health Insurance Survey

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

- Yes **GO TO Q9**
- No **GO TO Q10a**
- Don't have a health insurance premium **GO TO Q10a**
- Don't know/Not sure **GO TO Q10a**



2016 IDF Health Insurance Survey

9. 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

GO TO Q10a



2016 IDF Health 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.

10a. Do you have different deductibles, one for your prescriptions and one for your other medical expenses?

- Yes
- No
- Not sure

GO TO Q10b



2016 IDF Health Insurance Survey

10b. Do you know how much your health insurance deductible is?

- Yes **GO TO Q11**
- No **GO TO Q12**
- Don't have a deductible **GO TO Q12**
- Don't know/Not sure **GO TO Q12**



2016 IDF Health Insurance Survey

11. 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.

GO TO Q12



2016 IDF Health Insurance Survey

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

- Yes **GO TO Q13**
- No **GO TO Q14a**
- Don't know/Not sure **GO TO Q14a**



2016 IDF Health Insurance Survey

13. 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

GO TO Q14a



2016 IDF Health Insurance Survey

14a. 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"/>

GO TO Q14b

2016 IDF Health Insurance Survey

14b. In 2015, 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"/>

14c. Currently, for your 2016 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"/>

GO TO Q15a



2016 IDF Health Insurance Survey

15a. Does the person with PI have access to an immunologist who specializes in primary immunodeficiency?

- Yes **GO TO Q16a**
- No **GO TO Q15b**



2016 IDF Health Insurance Survey

15b. 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
- The immunologist is out of network and too expensive
- The patient does not need a specialist, the treating physician provides proper care
- Other

Other (please specify)

GO TO Q17a



2016 IDF Health 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”.

16a. Is this immunologist “in-network” for this person’s health insurance purpose or “out of network” for their health insurance?

- In-network **GO TO Q16c**
- Out-of-network **GO TO Q16b**
- Don't know/Not sure **GO TO Q16b**

2016 IDF Health Insurance Survey

16b. 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

GO TO QQ16c



2016 IDF Health Insurance Survey

16c. Approximately how far in miles does the person with PI have to travel, one way, to see the immunologist?

GO TO Q16d



2016 IDF Health Insurance Survey

16d. Since January 2016, 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.

GO TO Q17a



2016 IDF Health Insurance Survey

17a. Since January 2016, as a result of your health plan's rules, has the person with PI had any problems seeing any healthcare specialists?

Yes

No

17b. Since January 2016, 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

GO TO Q18a



2016 IDF Health Insurance Survey

18a. Since January 2016, how many emergency room visits (not overnight) has this person had?

18b. Since January 2016, how many times were they hospitalized overnight or longer?

GO TO Q19a



2016 IDF Health Insurance Survey

19a. Does the person with PI take antibiotics routinely or daily as part of the treatment for the patient's primary immunodeficiency?

- Yes **GO TO Q19b**
- No **GO TO Q19c**



2016 IDF Health Insurance Survey

19b. Approximately how many days since January 2016 have they used prescribed antibiotics?

GO TO Q19c

2016 IDF Health Insurance Survey

19c. Since January of 2016, how many infections, if any, did the person with PI have that required prescription antibiotics to help clear the infection?

GO TO Q20



2016 IDF Health Insurance Survey

20. Since January 2016, 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.

GO TO Q21



2016 IDF Health Insurance Survey

21. 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

GO TO Q22a



2016 IDF Health Insurance Survey

22a. Since January 2016, was there any time when the person with PI did not fill, or refill a prescription because of out-of-pocket costs?

Yes **GO TO Q22b**

No **GO TO Q23a**

2016 IDF Health Insurance Survey

22b. Please tell us which prescription drug(s) the person did not fill or refill.

Please enter one drug per text box.

Drug 1:

Drug 2:

Drug 3:

Drug 4:

Drug 5:

If you need to list additional prescription drugs, please use the text box below.

GO TO Q23a



2016 IDF Health Insurance Survey

23a. Since January 2016, was there any time when the person with PI skipped a medical test because of out-of-pocket costs?

Yes **GO TO Q23b**

No **GO TO Q24a**



2016 IDF Health Insurance Survey

23b. What kind of medical test(s) did they skip because of the cost

SELECT ALL THAT APPLY

Medical imaging (x-ray, CT scan, MRI, sonogram)

Lab/Blood work

Other

Other (please specify)

GO TO Q24a



2016 IDF Health Insurance Survey

24a. Since January 2016, was there any time when the person with PI skipped a medical treatment recommended by a doctor because of out-of-pocket costs?

Yes **GO TO Q24b**

No **GO TO 25a**

2016 IDF Health Insurance Survey

24b. Please tell us which medical treatments(s) the person skipped.

Please enter one skipped treatment per text box.

Treatment 1:	<input type="text"/>
Treatment 2:	<input type="text"/>
Treatment 3:	<input type="text"/>
Treatment 4:	<input type="text"/>
Treatment 5:	<input type="text"/>

If you need to list additional skipped treatments, please use the text box below.

GO TO Q25a



2016 IDF Health Insurance Survey

25a. Since January 2016, was there any time when the person with PI had a medical problem but did not go to a doctor or medical clinic because of out-of-pocket costs?

Yes **GO TO Q25b**

No **GO TO Q26a**

2016 IDF Health Insurance Survey

25b. Please tell us which medical problem(s) the person had but did not go to a doctor due to the cost.

Please enter one medical problem per text box.

Problem 1:

Problem 2:

Problem 3:

Problem 4:

Problem 5:

If you need to list additional medical problems, please use the text box below.

GO TO Q26a



2016 IDF Health Insurance Survey

26a. Since January 2016, was there any time when the person with PI did not see a specialist when the doctor recommended a referral to a specialist because of out-of-pocket costs?

Yes **GO TO Q26b**

No **GO TO Q27**



2016 IDF Health Insurance Survey

26b. If yes, please tell us which specialist(s) they did not see due to cost.

Please enter one specialist per text box.

Specialist 1:

Specialist 2:

Specialist 3:

Specialist 4:

Specialist 5:

If you need to add additional specialists, please use the text box below.

GO TO Q27



2016 IDF Health Insurance Survey

27. Since January 2016, 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
- None of the above
- Other

Other (please specify)

GO TO Q28a



2016 IDF Health Insurance Survey

28a. Since January 2016, 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 **GO TO Q28b**

No **GO TO Q29a**



2016 IDF Health Insurance Survey

28b. Since January 2016, have you had to declare bankruptcy due to the person's medical bills?

Yes **GO TO Q29a**

No **GO TO Q29a**



2016 IDF Health Insurance Survey

29a. 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 **GO TO Q30a**
- No **GO TO Q29b**



2016 IDF Health Insurance Survey

29b. 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)

GO TO Q_END_COMMENTS3



2016 IDF Health Insurance Survey

30a. 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 **GO TO Q31**
- Yes, IVIG **GO TO Q31**
- Yes, IM **GO TO Q33**
- No **GO TO Q30b**



2016 IDF Health Insurance Survey

30b. 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)

GO TO Q_END_COMMENTS3



2016 IDF Health Insurance Survey

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

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

GO TO Q32a



2016 IDF Health Insurance Survey

32a. Where does the person usually receive his/her Ig therapy?

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

Other (please specify)

GO TO Q32b

2016 IDF Health Insurance Survey

32b. 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"/>

Not sure

GO TO Q32c



2016 IDF Health Insurance Survey

32c. Not including travel time, how long does each therapy session usually take?

Hours

Minutes

Total time for therapy:

Not sure

GO TO Q33



2016 IDF Health Insurance Survey

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

Yes **GO TO Q34a**

No **GO TO Q35**



2016 IDF Health Insurance Survey

34a. Does the person (or the parent/caregiver of the person) need to take off from school or work to get their Ig therapy?

- Yes **GO TO Q34b**
- No **GO TO Q35**

2016 IDF Health Insurance Survey

34b. Since January 2016, 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

GO TO Q35



2016 IDF Health Insurance Survey

41. 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

GO TO Q42



2016 IDF Health Insurance Survey

42. Does the person's insurance plan cover both SCID and IVIG?

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

GO TO Q43



2016 IDF Health Insurance Survey

43. 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

GO TO Q44



2016 IDF Health Insurance Survey

44. 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

GO TO Q45a



2016 IDF Health Insurance Survey

45a. Since January 2016, has there been a time when the person skipped or delayed receiving their Ig therapy?

Yes **GO TO Q45b**

No **GO TO Q46**



2016 IDF Health Insurance Survey

45b. How many times since January 2016 have they skipped or delayed receiving their Ig therapy?

GO TO Q45c



2016 IDF Health Insurance Survey

45c. 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

45d. 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

2016 IDF Health 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.

46. 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 **GO TO Q47a**
- Coinsurance for Ig therapy **GO TO Q48a**
- I don't have any co-pays or coinsurance for Ig therapy **GO TO Q50a**
- Don't know/Not sure **GO TO Q50a**



2016 IDF Health Insurance Survey

47a. 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

Don't know/Not sure

GO TO Q47b



2016 IDF Health Insurance Survey

47b. Since September 2015, 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

GO TO Q50a

2016 IDF Health Insurance Survey

48a. Since September of 2015, 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

GO TO Q48b



2016 IDF Health Insurance Survey

48b. What is the percentage you must pay in coinsurance for the Ig therapy?

- 10%
- 15%
- 20%
- 25%
- 30%
- 40%
- 50%
- Don't know/Not sure
- Other

Other (please specify)

GO TO Q48c



2016 IDF Health Insurance Survey

48c. 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

Don't know/Not sure

GO TO Q48d



2016 IDF Health Insurance Survey

48d. Since January of 2016, 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

GO TO Q50a



2016 IDF Health 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.

50a. Is the person with PI currently receiving any financial assistance for co- pay, co-insurance or health insurance premium expenses?

- Yes **GO TO Q50b**
- No **GO TO Q51a**

2016 IDF Health Insurance Survey

50b. 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"/>

50c. Since January 2016, 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:

GO TO Q51a



2016 IDF Health Insurance Survey

51a. Since January 2016, due to health plan rules, has the person ever had a problem in getting his/her regular infusion?

Yes

GO TO Q51b

No

GO TO Q_END_COMMENTS1



2016 IDF Health Insurance Survey

51b. Since January 2016, which of the following events, if any, has the person experienced due to health plan rules?

SELECT ALL THAT APPLY

- 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)

51c. Since January 2016, how many times have they experienced a problem getting their regular infusion?

GO TO Q_END_COMMENTS1



2016 IDF Health Insurance Survey

Q_END_COMMENTS1.

Since January 2016, 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.

GO TO Q_END_COMMENTS2



2016 IDF Health Insurance Survey

Q_END_COMMENTS2.

Since January 2016, 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.

GO TO Q_END_COMMENTS3



2016 IDF Health Insurance Survey

Q_END_COMMENTS3.

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.

GO TO Q57a



2016 IDF Health Insurance Survey

57a. What state do you live in?

57b. Please enter your five-digit zip code below.

57new1a. Including yourself, how many adults (age 18 years old or older) currently live in your household?

(1 to 9 adults, Refused)

- 1 adult **GO TO Q57new1b**
- 2 adults **GO TO Q57new1c**
- 3 adults **GO TO Q57new1d**
- 4 adults **GO TO Q57new1e**
- 5 adults **GO TO Q57new1f**
- 6 adults **GO TO Q57new1g**
- 7 adults **GO TO Q57new1h**
- 8 adults **GO TO Q57new1i**
- 9 adults **GO TO Q57new1j**
- Refused **GO TO Q57new2a**



2016 IDF Health Insurance Survey

57new1b. You stated there is one adult in your household. How old are you?

Adult 1 (18 years old to 65 years old or older)

GO TO Q57new2a

57new1c. You stated there are two adults in your household. Please select the age of each adult in the household.

Adult 1 (18 years old to 65 years old or older)

Adult 2 (18 years old to 65 years old or older)

*57new1d...j Will cycle up to 9 adults

GO TO Q57new2a



2016 IDF Health Insurance Survey

57new2a. How many children (Infants and up to 17 years old) currently live in your household?

(0 to 9 children)

- 0 children **GO TO Q57c**
- 1 child **GO TO Q57new2b**
- 2 children **GO TO Q57new2c**
- 3 children **GO TO Q57new2d**
- 4 children **GO TO Q57new2e**
- 5 children **GO TO Q57new2f**
- 6 children **GO TO Q57new2g**
- 7 children **GO TO Q57new2h**
- 8 children **GO TO Q57new2i**
- 9 children **GO TO Q57new2j**
- Refused **GO TO Q57c**



2016 IDF Health Insurance Survey

57new2b. You stated there is one child in your household. How old is this child?

Child 1 (Younger than 1 years old to 17 years old)

GO TO Q57c

57new2c. You stated there are two children in your household Please select the ages of each child in the household.

Child 1 (Younger than 1 years old to 17 years old)

Child 2 (Younger than 1 years old to 17 years old)

*57new2d...j Will cycle up to 9 children

GO TO Q57c



2016 IDF Health Insurance Survey

57c. 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)

57d. 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)

57e. 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

GO TO Q57fnew



2016 IDF Health Insurance Survey

57fnew. What was the person's total household income last year?

Please use whole dollar amounts. For example: if total income is \$45,000, please enter 45000. Do not enter \$ or .

If 57fnew is left blank:

57f. Looking at the income ranges below, 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
- Don't know/Not sure

2016 IDF Health Insurance Survey

That completes our survey! Please click Done to submit your survey.

Thank you for your time and participation!

If you have any questions or concerns about this project, please contact Tiffany Henderson, Survey Research Analyst at IDF. She can be reached at: 1.800.296.4433.