

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

The purpose of this survey is to learn more about the treatment and care for patients with Severe Combined Immunodeficiency (SCID), Wiskott-Aldrich Syndrome (WAS), or Chronic Granulomatous Disease (CGD).

The ultimate goal of the project is to better understand what non-medical care is provided to these patients and their families, and how this care impacts their lives. The results from this survey will be used to help inform healthcare providers along with patient organizations. Results will also be used to create a manuscript for publication in peer reviewed journals.

The entire survey should, depending on your answers, take approximately 30-45 minutes to complete.

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.

There may be some questions that make you sad or will ask you to think about a difficult time in your life. You may refuse to answer questions or discontinue the survey at any time. 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 the Immune Deficiency Foundation. She can be reached at: 1.800.296.4433.

\* 1. 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 the "Disagree" button.

Agree

**GO TO PAGE 2**

Disagree

**END SURVEY**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 2. Do you or does someone in your household have SCID, WAS or CGD?

- Yes, SCID     **GO TO PAGE 3**
- Yes, WAS     **GO TO PAGE 10**
- Yes, CGD     **GO TO PAGE 17**
- No     **END SURVEY**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* **3.** How many people have ever been born with SCID in your household?

- 0 GO TO PAGE 4**
- 1 GO TO PAGE 5**
- 2 GO TO PAGE 6**
- 3 GO TO PAGE 7**
- 4 GO TO PAGE 8**
- 5 GO TO PAGE 9**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

YOU STATED NO ONE IN YOUR HOUSEHOLD HAS EVER BEEN BORN WITH SCID.

IF THIS IS CORRECT, PLEASE CLICK THE "NEXT" BUTTON NOW.

IF THIS IS NOT CORRECT, PLEASE CLICK THE "PREV" BUTTON AND REVIEW YOUR ANSWER.

**IF NEXT IS CLICKED, END SURVEY**

**IF PREV IS CLICKED GO TO PAGE 3**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

4. You said {{ Q3 }} child has been born with SCID in your household.

Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
---------------------------------	-------------------------------------	-----------	------------------

Please  
answering  
the  
following  
questions  
about this  
child:

**GO TO PAGE 24**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

5. You said {{ Q3 }} children have been born with SCID in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

6. You said {{ Q3 }} children have been born with SCID in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 25**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

7. You said {{ Q3 }} children have been born with SCID in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 25**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

8. You said {{ Q3 }} children have been born with SCID in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 25**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 9. How many people have ever been born with WAS in your household?

- 0 GO TO PAGE 11**
- 1 GO TO PAGE 12**
- 2 GO TO PAGE 13**
- 3 GO TO PAGE 14**
- 4 GO TO PAGE 15**
- 5 GO TO PAGE 16**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

YOU STATED NO ONE IN YOUR HOUSEHOLD HAS EVER BEEN BORN WITH WAS.

IF THIS IS CORRECT, PLEASE CLICK THE "NEXT" BUTTON NOW.

IF THIS IS NOT CORRECT, PLEASE CLICK THE "PREV" BUTTON AND REVIEW YOUR ANSWER.

**IF NEXT IS CLICKED, END SURVEY**

**IF PREV IS CLICKED GO TO PAGE 10**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

10. You said {{ Q9 }} child has been born with WAS in your household.

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Please answering the following questions about this child:	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 26**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

11. You said {{ Q9 }} children have been born with WAS in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 27**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

12. You said {{ Q9 }} children have been born with WAS in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 27**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

13. You said {{ Q9 }} children have been born with WAS in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 27**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

14. You said {{ Q9 }} children have been born with WAS in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 27**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

15. How many people have ever been born with CGD in your household?

- 0 GO TO PAGE 18
- 1 GO TO PAGE 19
- 2 GO TO PAGE 20
- 3 GO TO PAGE 21
- 4 GO TO PAGE 22
- 5 GO TO PAGE 23

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

YOU STATED NO ONE IN YOUR HOUSEHOLD HAS EVER BEEN BORN WITH CGD.

IF THIS IS CORRECT, PLEASE CLICK THE "NEXT" BUTTON NOW.

IF THIS IS NOT CORRECT, PLEASE CLICK THE "PREV" BUTTON AND REVIEW YOUR ANSWER.

**IF NEXT IS CLICKED, END SURVEY**

**IF PREV IS CLICKED GO TO PAGE 17**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

16. You said {{ Q15 }} child has been born with CGD in your household.

Currently Living or  
Deceased

Current Age or  
Age When Deceased

Diagnosis

Age of Diagnosis

Please  
answering  
the  
following  
questions  
about this  
child:

**GO TO PAGE 28**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

17. You said {{ Q15 }} children have been born with CGD in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 29**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**18.** You said {{ Q15 }} children have been born with CGD in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 29**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

19. You said {{ Q15 }} children have been born with CGD in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 29**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

20. You said {{ Q15 }} children have been born with CGD in your household. Please answering the following questions about each child:

	Currently Living or Deceased	Current Age or Age When Deceased	Diagnosis	Age of Diagnosis
Child 1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child 5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**GO TO PAGE 29**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**IF YOU HAVE NO SURVIVING CHILDREN WITH WAS LIVING IN YOUR HOUSEHOLD PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH SCID THAT PASSED AWAY.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 30**



## **Non-medical Care Survey for Patients with Primary Immunodeficiency Disease**

**IF YOU HAVE MORE THAN ONE CHILD WITH SCID CURRENTLY LIVING IN YOUR HOUSEHOLD, PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH SCID.**

**IF YOU HAVE NO SURVIVING CHILDREN WITH SCID LIVING IN YOUR HOUSEHOLD PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH SCID THAT PASSED AWAY.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 30**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**IF YOU HAVE NO SURVIVING CHILDREN WITH WAS LIVING IN YOUR HOUSEHOLD PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH WAS THAT PASSED AWAY.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 30**

## **Non-medical Care Survey for Patients with Primary Immunodeficiency Disease**

**IF YOU HAVE MORE THAN ONE CHILD WITH WAS CURRENTLY LIVING IN YOUR HOUSEHOLD, PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH WAS.**

**IF YOU HAVE NO SURVIVING CHILDREN WITH WAS LIVING IN YOUR HOUSEHOLD PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH WAS THAT PASSED AWAY.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 30**

**IF YOU HAVE NO SURVIVING CHILDREN WITH CGD LIVING IN YOUR HOUSEHOLD PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH CGD THAT PASSED AWAY.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 30**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**IF YOU HAVE MORE THAN ONE CHILD WITH CGD CURRENTLY LIVING IN YOUR HOUSEHOLD, PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH WAS CGD.**

**IF YOU HAVE NO SURVIVING CHILDREN WITH CGD LIVING IN YOUR HOUSEHOLD PLEASE ANSWER THE QUESTIONS BASED ON YOUR YOUNGEST CHILD WITH CGD THAT PASSED AWAY.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 30**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

### 21. Has your child ever undergone the following treatments:

	Previously, but not now	Currently receiving	Never
Ig Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prophylactic Antibiotic Therapy (Prophylactic Antibiotic Therapy is defined as antibiotics prescribed for 60 days or more.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Antifungal Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**GO TO PAGE 31**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 22. Has your child ever received a bone marrow transplant or is currently undergoing the transplantation process?

- Yes, my child received a bone marrow transplant **GO TO PAGE 35**
- Yes, my child is currently undergoing the transplant process **GO TO PAGE 35**
- No, my child died before the bone marrow transplant occurred **GO TO PAGE 53**
- No, my child never had a bone marrow transplant/not planning to have a bone marrow transplant **GO TO PAGE 32**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 23. Has your child ever completed gene therapy or is currently undergoing the gene therapy process?

- Yes, my child completed gene therapy **GO TO PAGE 34**
- Yes, my child currently undergoing the gene therapy process **GO TO PAGE 34**
- No, my child died before gene therapy occurred **GO TO PAGE 53**
- No, my child never completed gene therapy/not planning to complete gene therapy **GO TO PAGE 33**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 24. Has your child ever undergone a splenectomy or is currently undergoing the splenectomy process?

- Yes, my child had a splenectomy **GO TO PAGE 50**
- Yes, my child is currently undergoing the splenectomy process **GO TO PAGE 50**
- No, my child died before the splenectomy occurred **GO TO PAGE 53**
- No, my child never had a splenectomy/not planning to have a splenectomy **GO TO PAGE 53**

**YOU INDICATED YOUR CHILD HAS RECEIVED OR WILL UNDERGO GENE THERAPY. WHEN “THE TRANSPLANT” IS MENTIONED IN THIS SURVEY, WE ARE REFERRING TO GENE THERAPY.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 35**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

25. At what age was the transplant done/will the transplant be done?

26. Please provide the name and location of the hospital where the transplantation was performed/will be performed below:

**Name of Hospital**

**City/Town**

**State/Province (if in the United States)**

**ZIP/Postal Code (if in the United States)**

**Country**

27. What type of doctor performed/will perform the transplant?

- Oncologist
- Hematologist
- Immunologist
- Don't Know/Not Sure
- Other

Other (Please specify)

\* 28. Who was/will be the donor?

- Used/Using patient's stem cells **GO TO PAGE 45**
- Sibling donor **GO TO PAGE 36**
- Parent donor **GO TO PAGE 45**
- Unrelated donor **GO TO PAGE 45**
- Used/Using umbilical cord blood **GO TO PAGE 45**
- Don't Know/Not Sure **GO TO PAGE 45**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 29. At the hospital that performed the procedure, was the sibling donor offered SIBLING DONOR COUNSELING?

Yes, the hospital offered counseling

**GO TO PAGE 37**

No, the hospital did not offer counseling

**GO TO PAGE 40**

No, the sibling was/is too young

**GO TO PAGE 45**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 30. Did your child's sibling complete the counseling offered by the hospital?

- Yes, the sibling completed the counseling offered by the hospital **GO TO PAGE 42**
- No, the sibling STARTED but DID NOT complete the counseling offered by the hospital **GO TO PAGE 38**
- No, the sibling did not complete ANY counseling offered by the hospital **GO TO PAGE 39**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

31. Why didn't your child's sibling complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 32. Did your child's sibling complete donor counseling somewhere else?

- Yes **GO TO PAGE 41**
- No **GO TO PAGE 42**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

33. Why didn't your child's sibling complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 34. Did your child's sibling complete donor counseling somewhere else?

- Yes **GO TO PAGE 42**
- No **GO TO PAGE 45**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 35. Would your child's sibling have liked to receive sibling donor counseling?

Yes

**GO TO PAGE 45**

No

**GO TO PAGE 44**

My child's sibling(s) received counseling somewhere else

**GO TO PAGE 42**



**YOU STATED YOUR CHILD'S SIBLING STARTED SIBLING DONOR COUNSELING OFFERED BY THE HOSPITAL, BUT COMPLETED COUNSELING SOMEWHERE ELSE.**

**FOR THE FOLLOWING QUESTIONS, PLEASE THINK ABOUT THE COUNSELING THE SIBLING RECEIVED SOMEWHERE ELSE OTHER THAN THE HOSPITAL.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 42**

**36. Who provided the sibling donor counseling?**

Social Worker

Psychologist

Chaplain

Don't Know/Not sure

Other

Other (Please specify)

**37. Who paid for the counseling?**

**\* 38. Please rate your satisfaction with the donor counseling your child's sibling received:**

Very Satisfied                      **GO TO PAGE 45**

Satisfied                              **GO TO PAGE 43**

Neither satisfied or                **GO TO PAGE 43**

dissatisfied Dissatisfied        **GO TO PAGE 43**

Very Dissatisfied                 **GO TO PAGE 43**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

39. You stated you were {{ Q38 }} with the counseling the sibling received. What more could sibling donor counseling have provided?

**GO TO PAGE 45**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

40. There are many reasons why people decide not to participate in counseling, please share the sibling's reason(s) below:

**GO TO PAGE 45**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 41. Did your child have complications related to the transplant?

- Yes **GO TO PAGE 46**
- No **GO TO PAGE 47**
- Transplant has not happened yet **GO TO PAGE 48**
- Don't Know/Not Sure **GO TO PAGE 47**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

42. Did the complications require overnight hospitalization?

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

43. Are the complications on-going or are they resolved?

- The complications are on-going
- All complications are now resolved
- Some are on-going, some are resolved
- Don't Know/Not Sure

**GO TO PAGE 47**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

44. How often was/is your child followed up by their transplant doctor after the transplant was completed?

- Once a month
- Every few months
- Once a year
- Once every 1 to 2 years
- Once every 2 to 5 years
- Once every 5 years or more
- Don't Know/Not Sure
- Other

Other (Please specify)

**GO TO PAGE 48**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 45. Did/Will your family require housing/lodging during your child's transplantation process?

Yes **GO TO PAGE 49**

No **GO TO PAGE 53**



46. How many times did/will your child or your family need housing/lodging?

- 1 – 5 times
- 6 – 10 times
- More than 10

47. Who paid/will pay for the housing/lodging?

48. Have you ever had difficulty finding housing/lodging for your child or your family?

Yes

No

**GO TO PAGE 53**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

49. At what age was the splenectomy done/will the splenectomy be done?

50. Please provide the name and location of the hospital where the splenectomy was performed/will be performed below:

**Name of Hospital**

**City/Town**

**State/Province (if in the United States)**

**ZIP/Postal Code (if in the United States)**

**Country**

51. What type of doctor performed/will perform the splenectomy?

- Oncologist
- Hematologist
- Immunologist
- Don't Know/Not Sure
- Other

Other (Please specify)

**GO TO PAGE 51**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 52. Did your child have complications related to the splenectomy?

- Yes **GO TO PAGE 52**
- No **GO TO PAGE 53**
- Splenectomy has not happened yet **GO TO PAGE 53**
- Don't Know/Not Sure **GO TO PAGE 53**

53. Did the complications require overnight hospitalization?

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

54. Are the complications on-going or are they resolved?

- The complications are on-going
- All complications are now resolved
- Some are on-going, some are resolved
- Don't Know/Not Sure

**GO TO PAGE 53**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

FOR THE NEXT QUESTIONS, YOU WILL BE ASKED ABOUT NON-MEDICAL SERVICES YOUR CHILD MAY OR MAY NOT HAVE RECEIVED.

WHEN ANSWERING THESE QUESTIONS PLEASE THINK ABOUT YOUR CHILD'S EXPERIENCE AT OR AROUND THE TIME OF THEIR INITIAL DIAGNOSIS AND TREATMENT (INCLUDING BONE MARROW TRANSPLANT, GENE THERAPY, OR SPLENECTOMY, IF APPLICABLE).

55. In your opinion, how necessary were the following?

	Very necessary	Somewhat necessary	Not necessary or unnecessary	Somewhat unnecessary	Very Unnecessary	Not Applicable
Counseling Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial Assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spiritual/Religious Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peer Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**GO TO PAGE 54**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

WHEN ANSWERING THESE QUESTIONS PLEASE THINK ABOUT YOUR CHILD'S EXPERIENCE AT OR AROUND THE TIME OF THEIR INITIAL DIAGNOSIS AND TREATMENT (INCLUDING BONE MARROW TRANSPLANT, GENE THERAPY, OR SPLENECTOMY, IF APPLICABLE).

\* 56. At the hospital, were you and your family offered FAMILY COUNSELING?

(Family counseling involves ALL members of your family.)

Yes, the hospital offered counseling

**GO TO PAGE 55**

No, the hospital did not offer counseling

**GO TO PAGE 58**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 57. Did your family complete family counseling offered by the hospital?

- Yes, we completed the family counseling offered by the hospital
- No, we STARTED but DID NOT complete the counseling offered by the hospital
- No, we did not complete ANY family counseling offered by the hospital

**GO TO PAGE 60**

**GO TO PAGE 56**

**GO TO PAGE 57**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

58. Why didn't your family complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 59. Did your family complete family counseling somewhere else?

- Yes            **GO TO PAGE 59**
- No                **GO TO PAGE 60**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

60. Why didn't your family complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 61. Did your family complete family counseling somewhere else?

- Yes **GO TO PAGE 60**
- No **GO TO PAGE 63**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 62. Would your family have liked to receive family counseling?

Yes

**GO TO PAGE 63**

No

**GO TO PAGE 62**

We received counseling somewhere else

**GO TO PAGE 60**

**YOU STATED YOUR FAMILY STARTED FAMILY COUNSELING OFFERED BY THE HOSPITAL, BUT COMPLETED COUNSELING SOMEWHERE ELSE.**

**FOR THE FOLLOWING QUESTIONS, PLEASE THINK ABOUT THE COUNSELING YOUR FAMILY RECEIVED SOMEWHERE ELSE OTHER THAN THE HOSPITAL.**

PLEASE CLICK ON THE "NEXT" BUTTON NOW.

**GO TO PAGE 60**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

63. Who provided the family counseling?

- Social Worker
- Psychologist
- Chaplain
- Don't Know/Not sure
- Other

Other (Please specify)

64. Who paid for the counseling?

\* 65. Please rate your satisfaction with the counseling your family received:

- Very Satisfied **GO TO PAGE 63**
- Satisfied **GO TO PAGE 61**
- Neither satisfied or **GO TO PAGE 61**
- dissatisfied Dissatisfied **GO TO PAGE 61**
- Very Dissatisfied **GO TO PAGE 61**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

66. You stated you were {{ Q65 }} with the counseling your family received. What more could family counseling have provided?

**GO TO PAGE 63**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

67. There are many reasons why people decide not to participate in counseling, please share your family's reason(s) below:

**GO TO PAGE 63**

\* 68. Does your child have any siblings?

Yes **GO TO PAGE 64**

No **GO TO PAGE 73**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**WHEN ANSWERING THESE QUESTIONS PLEASE THINK ABOUT YOUR CHILD'S EXPERIENCE AT OR AROUND THE TIME OF THEIR INITIAL DIAGNOSIS AND TREATMENT (INCLUDING BONE MARROW TRANSPLANT, GENE THERAPY, OR SPLENECTOMY, IF APPLICABLE).**

\* 69. At the hospital, were your child's siblings offered SIBLING COUNSELING?

(Sibling counseling includes your child's brother(s) and/or sister(s). This counseling is separate from sibling DONOR counseling.)

- Yes, the hospital offered counseling **GO TO PAGE 65**
- No, the hospital did not offer counseling **GO TO PAGE 68**
- No, the sibling(s) was/is too young **GO TO PAGE 73**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 70. Did your child's sibling(s) complete the counseling offered by the hospital?

- Yes, the sibling(s) completed the counseling offered by the hospital **GO TO PAGE 70**
- No, the sibling(s) STARTED but DID NOT complete the counseling offered by the hospital **GO TO PAGE 66**
- No, the sibling(s) did not complete ANY counseling offered by the hospital **GO TO PAGE 67**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

71. Why didn't your child's sibling(s) complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 72. Did your child's sibling(s) complete sibling counseling somewhere else?

- Yes      **GO TO PAGE 69**
- No        **GO TO PAGE 70**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

73. Why didn't your child's sibling(s) complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 74. Did your child's sibling(s) complete sibling counseling somewhere else?

- Yes **GO TO PAGE 70**
- No **GO TO PAGE 73**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 75. Would your child's sibling(s) have liked to receive sibling counseling?

Yes

**GO TO PAGE 73**

No

**GO TO PAGE 72**

My child's sibling(s) received counseling somewhere else

**GO TO PAGE 70**

**YOU STATED YOUR CHILD'S SIBLING(S) STARTED SIBLING COUNSELING OFFERED BY THE HOSPITAL, BUT COMPLETED COUNSELING SOMEWHERE ELSE.**

**FOR THE FOLLOWING QUESTIONS, PLEASE THINK ABOUT THE COUNSELING THE SIBLING(S) RECEIVED SOMEWHERE ELSE OTHER THAN THE HOSPITAL.**

**PLEASE CLICK ON THE "NEXT" BUTTON NOW.**

**GO TO PAGE 70**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

76. Who provided the sibling counseling?

- Social Worker
- Psychologist
- Chaplain
- Don't Know/Not sure
- Other

Other (Please specify)

77. Who paid for the counseling?

\* 78. Please rate your satisfaction with the counseling your child's sibling(s) received:

- Very Satisfied **GO TO PAGE 73**
- Satisfied **GO TO PAGE 71**
- Neither satisfied or **GO TO PAGE 71**
- dissatisfied Dissatisfied **GO TO PAGE 71**
- Very Dissatisfied **GO TO PAGE 71**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

79. You stated you were {{ Q78 }} with the counseling the sibling(s) received. What more could sibling counseling have provided?

**GO TO PAGE 73**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

80. There are many reasons why people decide not to participate in counseling, please share the sibling(s)'s reason(s) below:

**GO TO PAGE 73**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

WHEN ANSWERING THESE QUESTIONS PLEASE THINK ABOUT YOUR CHILD'S EXPERIENCE AT OR AROUND THE TIME OF THEIR INITIAL DIAGNOSIS AND TREATMENT (INCLUDING BONE MARROW TRANSPLANT, GENE THERAPY, OR SPLENECTOMY, IF APPLICABLE).

\* 81. At the hospital, was your child offered INDIVIDUAL COUNSELING?

(Individual counseling only involves your child; no other family member participates.)

Yes, the hospital offered counseling **GO TO PAGE 74**

No, the hospital did not offer counseling **GO TO PAGE 77**

No, my child was/is too young **GO TO PAGE 82**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 82. Did your child complete the individual counseling offered by the hospital?

- Yes, my child completed the individual counseling offered by the hospital **GO TO PAGE 79**
- No, my child STARTED but DID NOT complete the counseling offered by the hospital **GO TO PAGE 75**
- No, my child did not complete the individual counseling offered by the hospital **GO TO PAGE 76**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

83. Why didn't your child complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 84. Did your child complete individual counseling somewhere else?

- Yes      **GO TO PAGE 78**
- No        **GO TO PAGE 79**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

85. Why didn't your child complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 86. Did your child complete individual counseling somewhere else?

- Yes      **GO TO PAGE 79**
- No        **GO TO PAGE 82**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 87. Would your child have liked to receive individual counseling?

- Yes **GO TO PAGE 82**
- No **GO TO PAGE 81**
- We received counseling somewhere else **GO TO PAGE 79**

**YOU STATED YOUR CHILD STARTED INDIVIDUAL COUNSELING OFFERED BY THE HOSPITAL,  
BUT COMPLETED COUNSELING SOMEWHERE ELSE.**

**FOR THE FOLLOWING QUESTIONS, PLEASE THINK ABOUT THE INDIVIDUAL COUNSELING YOUR  
CHILD RECEIVED SOMEWHERE ELSE OTHER THAN THE HOSPITAL.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 79**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

88. Who provided the individual counseling for your child?

- Social Worker
- Psychologist
- Chaplain
- Don't Know/Not sure
- Other

Other (Please specify)

89. Who paid for the counseling?

\* 90. Please rate your satisfaction with the individual counseling your child received:

- Very Satisfied **GO TO PAGE 82**
- Satisfied **GO TO PAGE 80**
- Neither satisfied or dissatisfied **GO TO PAGE 80**
- Dissatisfied **GO TO PAGE 80**
- Very Dissatisfied **GO TO PAGE 80**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

91. You stated you were {{ Q90 }} with the counseling your child received. What more could the individual counseling have provided?

**GO TO PAGE 82**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

92. There are many reasons why people decide not to participate in counseling, please share your child's reason(s) below:

**GO TO PAGE 82**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

WHEN ANSWERING THESE QUESTIONS PLEASE THINK ABOUT YOUR CHILD'S EXPERIENCE AT OR AROUND THE TIME OF THEIR INITIAL DIAGNOSIS AND TREATMENT (INCLUDING BONE MARROW TRANSPLANT, GENE THERAPY, OR SPLENECTOMY, IF APPLICABLE).

\* 93. At the hospital, were you and your family offered GENETIC COUNSELING?

(Genetic counseling provides information and support for families who are at risk for genetic disorders.)

Yes, the hospital offered counseling

**GO TO PAGE 83**

No, the hospital did not offer counseling

**GO TO PAGE 86**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 94. Did your family complete the genetic counseling offered by the hospital?

- Yes, we completed the genetic counseling offered by the hospital **GO TO PAGE 88**
- No, we STARTED but DID NOT complete the counseling offered by the hospital **GO TO PAGE 84**
- No, we did not complete ANY genetic counseling offered by the hospital **GO TO PAGE 85**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

95. Why didn't your family complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 96. Did your family complete genetic counseling somewhere else?

- Yes      **GO TO PAGE 87**
- No        **GO TO PAGE 88**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

97. Why didn't your family complete counseling?

PLEASE CHECK ALL THAT APPLY

- Did not have time, too busy
- Scheduling conflict
- Uninterested
- Prefer to talk to family or friends, not a counselor
- Other

Other (Please specify)

\* 98. Did your family complete genetic counseling somewhere else?

- Yes **GO TO PAGE 88**
- No **GO TO PAGE 91**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

99. Would your family have liked to receive genetic counseling?

- Yes **GO TO PAGE 91**
- No **GO TO PAGE 92**
- We received counseling somewhere else **GO TO PAGE 88**

**YOU STATED YOUR FAMILY STARTED GENETIC COUNSELING OFFERED BY THE HOSPITAL, BUT COMPLETED COUNSELING SOMEWHERE ELSE.**

**FOR THE FOLLOWING QUESTIONS, PLEASE THINK ABOUT THE GENETIC COUNSELING YOUR FAMILY RECEIVED SOMEWHERE ELSE OTHER THAN THE HOSPITAL.**

PLEASE CLICK THE "NEXT" BUTTON NOW.

**GO TO PAGE 88**

100. Who provided the genetic counseling?

Social Worker

Psychologist

Chaplain

Don't Know/Not sure

Other

Other (Please specify)

101. Who paid for the counseling?

\* 102. Please rate your satisfaction with the counseling family received:

Very Satisfied **GO TO PAGE 89**

Satisfied **GO TO PAGE 91**

Neither satisfied or dissatisfied **GO TO PAGE 91**

Dissatisfied **GO TO PAGE 91**

Very Dissatisfied **GO TO PAGE 91**



103. You stated you were {{ Q102 }} with the counseling your family received. What more could genetic counseling have provided?

**GO TO PAGE 91**

104. There are many reasons why people decide not to participate in counseling, please share your family's reason(s) below:

**GO TO PAGE 91**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

105. What is your child's primary health insurance at the time of initial diagnosis and treatment?

- Employer Sponsored Group Plan (Parent or Patient may be the policy holder)
- Individual Policy (For individuals or family – NOT offered by an employer)
- COBRA
- Medicaid
- Medicare
- State Children's Health Insurance Plan
- Self-paying
- Don't Know/Not Sure
- Other

Other (Please specify)

\* 106. Does your child have secondary health insurance at the time of initial diagnosis and treatment?

- Yes                    **GO TO PAGE 92**
- No                        **GO TO PAGE 93**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

107. What was your child's secondary health insurance?

- Employer Sponsored Group Plan (Parent or Patient may be the policy holder)
- Individual Policy (For individuals or family – NOT offered by an employer)
- Medicaid
- Medicare Supplemental Plan
- Medicare Advantage Plan
- TRICARE
- Don't Know/Not Sure
- Other

Other (Please specify)

**GO TO PAGE 93**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**NOW PLEASE THINK ABOUT YOUR CHILD'S EXPERIENCE OVERALL, FROM TIME OF INITIAL DIAGNOSIS UP TO TODAY, WHEN ANSWERING THE FOLLOWING QUESTIONS:**

108. Have your child's physicians ever asked if you would like more information about non-medical support services?

- Always
- Often
- Sometimes
- Rarely
- Never

109. Have your child's physicians ever mentioned or offered respite care?

- Yes
- No

110. Have your child's physicians ever mentioned or offered palliative care?

- Yes
- No
- Not Applicable

111. Did/Does your child have an active social worker or case worker?

- My child had/has an active social worker
- My child had/has an active case worker
- My child did/does not have an active social or case worker

**GO TO PAGE 94**

112. How satisfied are you with the coordination of care your child received/receives?

- Very Satisfied
- Satisfied
- Neither satisfied or dissatisfied
- Dissatisfied
- Very Dissatisfied

113. Has your child and/or your family ever received financial assistance for copay, co-insurance, health insurance premium, housing/lodging or travel expenses (e.g., gas, parking)?








- Yes, from a foundation(s) ONLY
- Yes, by self-fundraising ONLY
- Yes, from a foundation(s) and self-fundraising
- No

**GO TO PAGE 95**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

114. Please rank the following types of support in order of importance when thinking about your child's non-medical care:

1 = Very Important      7 = Least Important

	<input type="text"/>	Counseling (e.g., Family, Sibling, Donor, Individual)
	<input type="text"/>	Medical Bill Assistance
	<input type="text"/>	Housing/Lodging Assistance
	<input type="text"/>	Respite Care
	<input type="text"/>	Palliative Care
	<input type="text"/>	Spiritual/Religious Support
	<input type="text"/>	Peer Support

**GO TO PAGE 96**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 115. Currently, how old is your child?

- Younger than 5 years old **GO TO PAGE 97**
- 5 to 12 years old **GO TO PAGE 97**
- 13 to 18 years old **GO TO PAGE 97**
- 19 to 24 years old **GO TO PAGE 103**
- 25 to 44 years old **GO TO PAGE 103**
- My child is deceased **GO TO PAGE 107**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 116. Is your child currently in school (grades K-12)?

- Yes **GO TO PAGE 98**
- No **GO TO PAGE 99**
- My child is not school age yet **GO TO PAGE 102**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

117. What grade is your child in?

118. Is your child in a special program in school?

(Special needs programs are designated for students with learning, behavior, mental health, medical, or intellectual disabilities.)

Yes

No

**GO TO PAGE 101**

\*119. Is your child homeschooled?

Yes **GO TO PAGE 100**

No **GO TO PAGE 101**

120. What grade is your child in?

**GO TO PAGE 101**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

121. Does your child receive assistance for learning beyond regular school?

Yes

No

122. Has your child ever been required to repeat a year of school?

Yes

No

123. Has your child ever had to take a leave of absence from school or be temporarily homeschooled because of his/her illness?

Yes

No

124. Did your child graduate high school?

Yes

No

Not Applicable

**GO TO PAGE 102**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**125. How has your child's condition impacted your CHILD'S life on a scale of 0-10?**

0 = No Impact 10 = Extremely High Impact

**126. How has your child's condition impacted YOUR daily life on a scale of 0-10?**

0 = No Impact 10 = Extremely High Impact

**GO TO PAGE 107**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

\* 127. What is your child's current employment status?

- |  |                       |
|--|-----------------------|
| <input type="radio"/> Employed full time   | <b>GO TO PAGE 104</b> |
| <input type="radio"/> Employed part time   | <b>GO TO PAGE 104</b> |
| <input type="radio"/> Unemployed, looking for work                                 | <b>GO TO PAGE 105</b> |
| <input type="radio"/> Student (e.g., Vocational Program, College, Graduate School) | <b>GO TO PAGE 105</b> |
| <input type="radio"/> Homemaker  | <b>GO TO PAGE 105</b> |
| <input type="radio"/> Disabled/too ill to work                                     | <b>GO TO PAGE 105</b> |
| <input type="radio"/> Don't Know/Not Sure  | <b>GO TO PAGE 105</b> |
| <input type="radio"/> Other  | <b>GO TO PAGE 105</b> |
| <input type="radio"/> Other (Please specify)                                       |                       |

128. What is your child's current occupation?

**GO TO PAGE 105**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

129. Has your child ever had work and/or school difficulties because of his/her illness?

Yes

No

130. Has your child ever lost a job because of his/her illness?

Yes

No

Never been employed

131. Has your child ever had to take a leave of absence from work/school because of his/her illness?

Yes

No

**GO TO PAGE 106**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

132. How has your child's condition impacted your CHILD'S life on a scale of 0-10?

0 = No Impact 10 = Extremely High Impact

133. How has your child's condition impacted YOUR daily life on a scale of 0-10?

0 = No Impact 10 = Extremely High Impact

**GO TO PAGE 107**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

134. CURRENTLY when thinking about your child's non-medical care, in your opinion how necessary are the following?

	Very necessary	Somewhat necessary	Not necessary or unnecessary	Somewhat unnecessary	Very Unnecessary	Not Applicable
Counseling Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial Assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spiritual/Religious Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peer Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**GO TO PAGE 108**

135. If you have any final comments that you wish to add, please use the text box below.

**GO TO PAGE 109**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

136. What is your child's date of birth?

Please enter as MM/DD/YYYY

Example: 01/01/2005

137. What is your child's gender?

- Male
- Female
- Refused

138. Is your child Hispanic or Latino?

- No, my child is not Hispanic or Latino
- Yes, my child is Hispanic or Latino

139. What is your child's race?

- White (non-Hispanic)
- African-American/Black
- Asian/Pacific Islander
- American Indian/Alaskan native
- More than one race
- Other

Other (Please specify)

**GO TO PAGE 110**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

140. Please provide the following information about your child:

State/Province

(If in the United States)

Country

141. What is the last grade or year of school completed by your child (if your child is 17 years old or younger, please select the last year of school YOU completed)?

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

142. What was your 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

**GO TO PAGE 111**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

**The questions below are for quality control purposes only:**

140. Please type in the initials to your first and last name, followed by the year YOU were born. For example, if your name is John M Smith, and you were born in 1977 please enter JS1977.

\* 146. Lastly, we may have questions or need clarification on some of your answers. May we contact you if we have any follow-up questions?

Yes **GO TO PAGE 112**

No **GO TO PAGE 113**

## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

145. Thank you! Please enter your contact information below:

Name

Email Address

**GO TO PAGE 113**



## Non-medical Care Survey for Patients with Primary Immunodeficiency Disease

Thank you for your participation, you have completed the Non-medical Care Survey for Patients with Primary Immunodeficiency Disease.

Please click "Done" to submit your survey.

If you have any questions or concerns, please contact Tiffany Henderson, Survey Research Analyst at the Immune Deficiency Foundation. She can be reached at: 1.800.296.4433.