

# Appendix A: Full Questionnaire

## SCREENER

This is an important study about caring for someone with a rare disease or condition, conducted by Greenwald & Associates on behalf of the National Alliance for Caregiving in partnership with Global Genes.

1. How old are you?

\_\_\_\_\_

2. Do you live in the United States?

Yes ..... 1  
No ..... 2

3. At any time in the last 12 months, have you provided unpaid care to a relative or friend age 18 years or older to help them take care of themselves?

This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, doing medical or nursing things, or visiting regularly to see how they are doing. This adult does not need to live with you.

If you are paid some amount as part of a Medicaid, state government, or grant program to care for a close family member in home, please select "yes".

Yes ..... 1  
No ..... 2

4. At any time in the last 12 months, have you provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability?

This kind of unpaid care is more than the normal care required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.

If you are paid some amount as part of a Medicaid, state government, or grant program to care for your own child in home, please select "yes".

Yes ..... 1  
No ..... 2

**IF LESS THAN 18 (Q1<18) OR OUTSIDE U.S. (Q2=2) OR NOT CAREGIVER (Q3=2 and Q4=2),  
TERMINATE.**

5. Did any of the [IF ADULT ONLY (Q3=1 and Q4=2): adults / IF CHILD ONLY (Q3=2 and Q4=1): children / IF BOTH (Q3=1 and Q4=1): adults or children] you cared for in the past year have what might be considered a rare disease or condition?

A rare disease is defined as a condition that affects fewer than 200,000 people in the United States.

- Yes ..... 1  
 No ..... 2 **TERMINATE**  
 Not sure ..... 3

6. In the past year, have you cared for more than one person who has a rare disease or condition?

- Yes ..... 1  
 No ..... 2  
 Not sure ..... 3

**CONFIRMATION OF CAREGIVING STATUS**

[IF CARING FOR ONE PERSON (Q6=2), SHOW: For the rest of the questions, please think about that adult or child you care for, or cared for in the past year, who has or had a rare disease or condition.]

[IF CARING FOR MORE THAN ONE PERSON (Q6=1 OR 3), SHOW: For the rest of the survey, please think about the person with a rare disease or condition who you have provided the **most care** to in the past year. If you have provided similar amounts of care to multiple people with a rare condition, please think about the person you have been caring for the longest.]

7. Are you currently providing care to this person, or was this something you did in the past 12 months and are no longer doing?

- Currently ..... 1  
 Past 12 months but not currently ..... 2

**INFORMATION ABOUT CARE RECIPIENT**

8. And {is/was} the person you {care/cared} for...

- Male ..... 1  
 Female ..... 2  
 Decline to respond ..... 3

9. {Are/Were} you related to the person you {care/cared} for?

- Yes ..... 1  
 No ..... 2

10. Who {are you caring/did you care} for?

*I {care/cared} for my \_\_\_\_\_.*

**IF FEMALE/DECLINE RELATIVE ((Q8=2 OR 3) and Q9=1), SHOW THESE RESPONSES:**

Aunt .....	1
Cousin .....	5
Daughter.....	6
Grandmother/Grandmother-in-law .....	10
Granddaughter .....	11
Mother .....	13
Mother-in-law.....	14
Niece .....	16
Sister .....	17
Sister-in-law.....	18
Spouse .....	20
Partner/Companion .....	4
Other relative [ <b>Specify:</b> _____] .....	30
Decline to respond.....	99

**IF MALE/DECLINE RELATIVE ((Q8=1 or 3) and Q9=1), SHOW THESE RESPONSES:**

Brother.....	2
Brother-in-law .....	3
Cousin .....	5
Father .....	7
Father-in-law.....	8
Grandfather/Grandfather-in-law .....	9
Grandson.....	12
Nephew .....	15
Son .....	19
Spouse .....	20
Partner/Companion .....	4
Uncle .....	21
Other relative [ <b>Specify:</b> _____] .....	30
Decline to respond.....	99

**IF NOT RELATIVE (Q9=2), SHOW THESE RESPONSES:**

Friend .....	41
Neighbor .....	42
Other [ <b>Specify:</b> _____].....	43
Decline to respond.....	99

11. **[IF CURRENT (Q7=1)]:** How old is your **[RELATION]**? Your best estimate is fine.

**[IF PAST (Q7=2)]:** How old was your **[RELATION]**, at the time you last provided care?  
Your best estimate is fine.

\_\_\_ \_\_\_ \_\_\_ years

Less than 1 year old ..... 998

Decline..... 999

11B. **[IF DECLINE (Q11=999)]:** {Is/Was} your **[RELATION]** age...?

0 to 9..... 1

10 to 17 ..... 2

18 to 24..... 3

25 to 29..... 4

30 to 39..... 5

40 to 49..... 6

50 to 64..... 7

65 or older..... 8

**CAREGIVING SITUATION**

12. How long {have you been providing/did you provide} care to your **[RELATION]**?

*Your best estimate of years of care is fine.*

\_\_\_ \_\_\_ years

Less than six months ..... 96

Six months to one year ..... 95

Not sure..... 98

13. Thinking about all the different things you {do/did} for your **[RELATION]**, about how many hours {do/did} you spend in an average week, helping your **[RELATION]**?

*Your best estimate of hours per week is fine.*

\_\_\_ \_\_\_ \_\_\_ hours

Less than 1 hour per week ..... 900

Constant care (24 hours a day, 7 days a week) ..... 901

Sporadic care, off and on ..... 902

Not sure..... 998

13B. **[IF SPORADIC / NOT SURE (Q13=902 OR 998)]:** On average, **[IF PAST (Q7=2):** over the period during which you provided care,] {do/did} you provide care for...?

- 0 to 8 hours a week ..... 1
- 9 to 20 hours a week..... 2
- 21 to 39 hours a week..... 3
- 40 or more hours a week ..... 4

14. Which of the following best describes where your **[RELATION]** {lives/lived at the time you provided care}?

- In your household ..... 1
- His or her own home ..... 2
- Someone else's home ..... 3
- Group home..... 4
- A nursing care or long-term care facility  
(or assisted living or hospital) ..... 5
- Or somewhere else? **[SPECIFY \_\_\_\_\_]**..... 6

**IF IN HOUSEHOLD (Q14=1), SKIP TO NEXT SECTION.**

**IF CHILD RECIPIENT (CRTYPE=1), PRE-PUNCH Q15=2 AND SKIP TO NEXT SECTION.**

15. **[IF ADULT CR (CRTYPE=2) AND NOT IN CG HH (Q14=2 or 3 or 6), ASK]:** {Does/Did} your **[RELATION]** live alone **[IF PAST (Q7=2):** at the time you provided care]?

- Yes ..... 1
- No ..... 2

**CAREGIVING TASKS**

16. **[IF ADULT RECIPIENT (CRTYPE=2)]:** Below is a list of things someone might help with, because a person cannot do these things by him/herself. Which of these things {do/did} you help your **[RELATION]** with?

**[IF CHILD RECIPIENT (CRTYPE=1)]:** Below is a list of things that someone might help a child do, if the child cannot do this by him or herself. Which of these things {do/did} you help your **[RELATION]** do, because he/she {is/was} less able to do this task than children of the same age without his/her condition?

	<i>ADL list</i>	Yes	No
a.	<b>[SHOW IF CR age is 4+ ((Q11&gt;3 AND Q11&lt;997) OR Q11B&gt;1)]:</b> Getting in and out of beds and chairs	1	2
b.	<b>[SHOW IF CR age is 5+ ((Q11&gt;4 AND Q11&lt;997) OR Q11B&gt;1)]:</b> Getting dressed	1	2
c.	<b>[SHOW IF CR age 4+ ((Q11&gt;3 AND Q11&lt;997) OR Q11B&gt;1)]:</b> Getting to and from the toilet	1	2
d.	<b>[SHOW IF CR age 6+ ((Q11&gt;5 AND Q11&lt;997) OR Q11B&gt;1)]:</b> Bathing or showering	1	2
e.	<b>[SHOW IF CR age 4+ ((Q11&gt;3 AND Q11&lt;997) OR Q11B&gt;1)]:</b> Dealing with incontinence or diapers	1	2
f.	<b>[SHOW IF CR age 3+ ((Q11&gt;2 AND Q11&lt;997) OR Q11B&gt;1)]:</b> Feeding him or her	1	2

17. **[IF DOES ADLS (ANY Q16 A thru F = 1)]:** How difficult {is/was} it for you to help with {these/those} kinds of tasks?

Not at all difficult				Very difficult
1	2	3	4	5

18. And (do/did) you provide help to your **[RELATION]** with...

	<i>IADL list</i>	Yes	No
a.	Managing finances, such as paying bills or filling out insurance claims	1	2
b.	<b>[IF ADULT (CRTYPE=2)]:</b> Grocery or other shopping	1	2
c.	<b>[IF ADULT (CRTYPE=2)]:</b> Housework, such as doing dishes, laundry, or straightening up	1	2
d.	<b>[IF ADULT (CRTYPE=2)]:</b> Preparing meals	1	2
e.	<b>[IF ADULT (CRTYPE=2)]:</b> Transportation, either by driving your <b>[RELATION]</b> or helping him/her get transportation	1	2
f.	Arranging or supervising outside services, such as nurses or aides	1	2
g.	Giving medicines, pills, or injections for his/her condition	1	2

19. {Do/Did} you help your [RELATION] with medical/nursing tasks?

This might include giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, or wound care. You could be monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

Yes ..... 1  
 No ..... 2

**IF NO MEDICAL/NURSING, SKIP TO Q23.**

**MEDICAL/NURSING TASKS**

20. **[IF DOES M/N TASKS (Q19=1), ASK]:** How difficult {is/was} it for you to do the medical/nursing tasks that {are/were} required to help your [RELATION]?

**SHOW DEFINITION ON SCREEN:** Medical/nursing tasks include: giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, wound care, monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

<b>Not at all difficult</b>				<b>Very difficult</b>
1	2	3	4	5

21. **[IF DOES M/N TASKS (Q19=1), ASK]:** Did anyone prepare you to do these tasks?

Yes ..... 1  
 No ..... 2  
 Not sure ..... 3

22. **[IF DOES M/N TASKS (Q19=1), ASK]:** How long {have you been doing/did you do} those medical/nursing tasks?

*Your best estimate is fine.*

\_\_\_ \_\_\_ years

Less than six months ..... 96  
 Six months to one year ..... 95  
 Not sure ..... 98

**OTHER SUPPORT**

23. {Has/Had} anyone else provided unpaid help to your [RELATION] during the last 12 months **[IF PAST (Q7=2): that you provided care]**?

Yes ..... 1  
 No ..... 2 **[SKIP TO Q27]**

24. **[IF HAS OTHER HELP (Q23=1), ASK]:** Who else {has provided/provided} unpaid help to your **[RELATION]** during the last 12 months? *Please select all that apply.*

He/She {gets/got} unpaid help from his/her...

- Parent (mother, father, step-parent) ..... 1
- Sibling (sister, brother, step-sibling) ..... 2
- [IF ADULT CR (CRTYPE=2)]:** Spouse or partner ..... 3
- [IF ADULT CR (CRTYPE=2)]:** Child (daughter, son, step-child) .. 4
- Grandparent ..... 5
- [IF ADULT CR (CRTYPE=2)]:** In-laws (parent-in-law, sister-in-law, brother-in-law) ..... 6
- Aunt or uncle ..... 7
- Cousin ..... 8
- [IF ADULT CR (CRTYPE=2)]:** Niece or nephew ..... 9
- [IF ADULT CR (CRTYPE=2)]:** Grandchild ..... 10
- Friend or neighbor ..... 11
- Other [**Specify:** \_\_\_\_\_] ..... 98
- Decline to respond..... 99

25. **[IF HAS OTHER HELP (Q23=1), ASK]:** Of all the other people who {help/helped} provide care to your **[RELATION]**, {are/were} any of them children under age 18?

- Yes ..... 1
- No..... 2

26. **[IF HAS OTHER HELP (Q23=1), ASK]:** Who would you consider to be the person who {provides/provided} most of the unpaid care for your **[RELATION]**?

- You (yourself) ..... 1
- Someone else..... 2
- We split it evenly..... 3

27. During the last 12 months, did your **[RELATION]** receive paid help from any aides, housekeepers, or other people who were paid to help him/her?

- Yes ..... 1
- No..... 2



**CAREGIVER INVOLVEMENT IN CARE PROCESS**

28. {Do/Did} you provide help to your [RELATION] by...

		Yes	No
a.	Advocating for him/her with health care providers, services, schools, or agencies	1	2
b.	Monitoring the severity of his/her condition so that you {can/could} adjust care accordingly	1	2
c.	Communicating with health care professionals like doctors, nurses, or social workers about his/her care	1	2
d.	Educating health care professionals about my [RELATION]'s rare condition	1	2
e.	Living away from home for more than 3 weeks to help get my [RELATION] the care he/she needed	1	2

29. Where {do/did} you go for help or information about caring for your [RELATION]'s condition? *Please select all that apply.*

- Condition-specific websites or organizations..... 1
- General rare disease or condition umbrella groups (e.g. Global Genes)..... 2
- General Internet searches ..... 3
- Doctor or health care professional..... 4
- Genetic specialist or counselor..... 5
- In-person support groups or others who know about or have experience with condition ..... 6
- Online support groups ..... 7
- Other [SPECIFY: \_\_\_\_\_]..... 8
- Never got help/information ..... 9
- Social media ..... 10
- NIH or other government health organizations ..... 11
- Academic or Medical conferences, journals, books, research..... 12

**DIAGNOSIS AND MISDIAGNOSIS**

30 What rare disease or condition {does/did} your [RELATION] have? [OPEN-ENDED]

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Unknown or undiagnosed..... 999999

31. {Do/Did} you feel your [RELATION]'s condition {has been/was} accurately diagnosed?

- Yes ..... 1
- No..... 2
- Not sure..... 3

32. {Does/Did} your [RELATION]'s condition result from some genetic issue or component?

- Yes ..... 1
- No..... 2
- Not sure..... 3

33. **[IF GENETIC (Q32=1), ASK]:** Did your [RELATION] or anyone in your [RELATION]'s family ever do any of the following things?

		Yes	No	Not Sure
a.	Get genetic testing	1	2	3
b.	See or consult with a genetic counselor	1	2	3

34. **[IF CARING FOR RELATIVE AND GENETIC (Q9=1 AND Q32=1), ASK]:** Do you or does anyone else in your family also have the same rare condition as your [RELATION]?

- Yes ..... 1
- No..... 2
- Decline to respond..... 3

**TREATMENT AND SYMPTOM MANAGEMENT**

35. To the best of your knowledge, {is/at the time you last were providing care, was} there any kind of:

		Yes	No	Not sure
a.	Treatment available for your [RELATION]'s actual condition?	1	2	3
b.	Treatment or therapy available for managing your [RELATION]'s symptoms?	1	2	3

36. **[IF AVAILABLE (Q35A=1 OR Q35B=1), ASK]:** How difficult {is/was} it for your **[RELATION]** to access:

		Not at all difficult				Very difficult
a.	<b>[IF AVAILABLE (Q35A=1), ASK]:</b> Treatment for his/her actual condition?	1	2	3	4	5
b.	<b>[IF AVAILABLE (Q35B=1), ASK]:</b> Treatment or therapy for managing his/her symptoms?	1	2	3	4	5

37. {Is/Was} your **[RELATION]** taking any prescription medication(s) to...

		Yes	No	Not sure
a.	Help treat his/her condition?	1	2	3
b.	Manage his/her symptoms?	1	2	3

**CLINICAL TRIALS**

38. {Has/Did} your **[RELATION]** ever {participated/participate} in any clinical trials?

- Yes ..... 1
- No ..... 2
- Not sure ..... 3

39. **[IF YES (Q38=1), ASK]:** Which of the following things have you done to help your **[RELATION]** participate in a clinical trial, if any? *Please select all that apply.*

- Research or find the clinical trial for your **[RELATION]** .....1
- Fill out forms or handle other paperwork, including insurance coverage or benefits .....2
- Coordinate care or communication between the clinical trial and your **[RELATION]**'s regular doctors or care providers .....3
- Provide or arrange transportation to and from the clinical trial .....4
- Pay for your **[RELATION]**'s travel costs or a place to live during the trial.....5
- Travel more than a 3-hour drive to get to the clinical trial location.....6
- Move away from your home for a period of a month or longer .....7
- Monitor your **[RELATION]**'s condition to provide documentation to the clinical trial after treatment .....8
- I {do/did} not help with clinical trials .....9

**SERVICE ACCESS**

40. Select any care or support services you feel your **[RELATION]** {needs/needed}, even if you {have been/were} unable to locate or find this kind of help.

1	Medical professional who {has/had} experience treating his/her condition
2	Pharmacy that {has/had} necessary medications
3	Genetic counselor
4	Clinical trials, to receive treatment for the condition
5	Complementary or alternative treatments
5	Case manager or social worker to help with support services
6	Educational support services or programs
7	Mental health professional, like a psychiatrist, therapist, or counselor
8	None needed
9	Not sure

**IF NONE OR NOT SURE (Q40=8 or 9), SKIP TO Q42.**

41. Of the care or support services you {feel/felt} your **[RELATION]** {needs/needed}, which {have been/were} difficult to find in his/her area or community?

**[SHOW ONLY THOSE SELECTED IN Q40]**

1	Medical professional who {has/had} experience treating his/her condition
2	Pharmacy that {has/had} needed medications
3	Genetic counselor
4	Clinical trials, to receive treatment for the condition
5	Complementary or alternative treatments
5	Case manager or social worker to help with support services
6	Educational support services or programs
7	Mental health professional, like a psychiatrist, therapist, or counselor
8	None needed
9	Not sure

42. In your experience as a caregiver, have you ever....

		Yes	No
a.	Requested information about how to get financial help for your [RELATION]?	1	2
b.	Used respite services where someone would take care of your [RELATION] to give you a break?	1	2
c.	Had an outside service provide transportation for your [RELATION] instead of you providing the transportation?	1	2
d.	Had modifications made in the house or apartment where your [RELATION] {lives/lived} to make things easier for him/her?	1	2
e.	Had a doctor, nurse, or social worker ask you about what you {need/needed} to help care for your [RELATION]?	1	2
f.	Had a doctor, nurse, or social worker ask you what you {need/needed} to take care of yourself?	1	2
g.	Had a virtual or online visit with a doctor who could care for or consult on your [RELATION]'s condition?	1	2
h.	Used an online support group for caregivers?	1	2

43. How much do you agree or disagree with each statement below?

		Strongly disagree	Disagree	Neither	Agree	Strongly agree
a.	Helping my [RELATION] {helps/helped} me feel close to him/her	1	2	3	4	5
b.	I {take/took} pride in improving my understanding of information about my [RELATION]'s condition	1	2	3	4	5
c.	I {feel/felt} like a valued part of my [RELATION]'s care team	1	2	3	4	5
d.	My [RELATION]'s local hospital {is/was} able to handle his/her condition	1	2	3	4	5

**WORKING, STUDYING**

44. At any time in the past year while you were providing care, were you also...

		Yes	No
a.	Employed?	1	2
b.	A student (full- or part-time)?	1	2

**IF NEITHER WORKING NOR STUDENT (Q44A=2 & Q44B=2), SKIP OUT OF SECTION TO Q47.  
IF STUDENT ONLY (Q44A=2 & Q44B=1), SKIP TO Q46.**

45. **[IF EMPLOYED (Q44A=1), ASK]:** Please think about the most recent time in the last year when you were both working and providing care to your **[RELATION]**. As a result of caregiving, did you ever experience any of these things at work?

		Yes	No
a.	Went in late, left early, or took time off during the day to provide care	1	2
b.	Took a leave of absence	1	2
c.	Went from working full time to part time, or cut back your hours	1	2
d.	Turned down a promotion	1	2
e.	Lost any of your job benefits	1	2
f.	Gave up working entirely or retired early	1	2

46. **[IF STUDENT (Q44B=1), ASK]:** Please think about the most recent time in the last year when you were both a student and providing care to your **[RELATION]**. As a result of caregiving, did you ever experience any of these things as a student?

		Yes	No
a.	Was late, left early, or otherwise missed class time to provide care	1	2
b.	Missed an assignment or exam	1	2
c.	Cut back from being a full-time to part-time student	1	2
d.	Dropped a course	1	2
e.	Gave up school entirely	1	2
f.	Took more classes online rather than in person	1	2

**WELL-BEING**

47. How emotionally stressful would you say that caring for your **[RELATION]** {is/was} for you?

- 1 – Not at all stressful ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 – Very stressful..... 5

48. How much of a physical strain would you say that caring for your [RELATION] {is/was} for you?

- 1 – Not a strain at all..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 – Very much a strain..... 5

49. {How would you describe your physical health? / When you were last caregiving, was your physical health...?}

- Excellent..... 5
- Very good ..... 4
- Good..... 3
- Fair ..... 2
- Poor..... 1

50. {And how would you describe your emotional or mental health? / When you were last caregiving, was your emotional or mental health...?}

- Excellent..... 5
- Very good ..... 4
- Good..... 3
- Fair ..... 2
- Poor..... 1

51. Thinking about your experience as a caregiver, how much do you agree or disagree with each statement below?

		Strongly disagree	Disagree	Neither	Agree	Strongly agree
a.	I {find/found} it difficult to take care of my own health	1	2	3	4	5
b.	I {feel/felt} alone	1	2	3	4	5
c.	I {struggle/have struggled} with a sense of loss for what my [RELATION]'s life would {be/have been} without his/her condition	1	2	3	4	5
d.	I {have been/was} unable to maintain friendships I had prior to being a caregiver for my [RELATION]	1	2	3	4	5
e.	I {am/was} able to get some time to myself when I {need/needed} it	1	2	3	4	5
f.	My role in caring for my [RELATION] {has had/had} a positive impact on my family	1	2	3	4	5
g.	My role as a caregiver {gives/gave} me a sense of purpose in my life	1	2	3	4	5

**IF PARENT CARING FOR MINOR CHILD (CRTYPE=1 AND Q10=6 or 19), SKIP TO NEXT SECTION.**

52. **[IF NOT PARENT CARING FOR MINOR CHILD ((CRTYPE=1 AND Q10≠6 or 19) OR CRTYPE=2), ASK]:** Do you feel you had a choice in taking on this responsibility of caring for your [RELATION]?

- Yes ..... 1
- No ..... 2

**FINANCES, LEGAL**

53. {What is/At the time you last provided care, what was} the insurance status of your [RELATION]? *Please select all that apply.*

- Insured through Medicare ..... 1
- Insured through Medicaid ..... 2
- Insured through state children’s health insurance plan (CHIP) ..... 3
- Privately insured, either through employer plan or purchased on own ..... 4
- Uninsured ..... 5
- Not sure ..... 9



54. How much of a financial strain would you say that caring for your [RELATION] {is/was} for you?

- 1 – Not a strain at all..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 – Very much a strain..... 5

55. Have you personally ever experienced any of these financial impacts because of your role in providing care to your [RELATION]?

		Yes	No
a.	Filed for bankruptcy (medical or personal)	1	2
b.	Took on more personal debt (credit cards, personal loans, or home equity lines of credit)	1	2
c.	Used up your personal savings	1	2
d.	Left household bills unpaid or paid late (electric, gas, cable, phone)	1	2
e.	Had to sell a large asset (home, boat, business, or rental property)	1	2
f.	Moved to a less expensive home or apartment	1	2
g.	Stopped saving for long-term goals, like retirement or education savings	1	2
h.	Cut back household spending in areas like travel, entertainment, eating out, or cable/phone	1	2

56. **[IF PARENT CARING FOR OWN CHILD CR (Q10=6 or 19 AND CRTYPE=1), ASK]:** {Do/Did} you worry about your ability to pay for your [RELATION]’s care?

**[IF NOT PARENT CARING FOR CHILD CR (Q10≠6 or 19 AND CRTYPE=1), ASK]:** {Do/Did} you worry about your [RELATION]’s family’s ability to pay for his/her care?

**[IF ADULT CR (CRTYPE=2), ASK]:** {Do/Did} you worry about your [RELATION]’s ability to pay for his/her own care?

- Yes ..... 1
- No ..... 2
- Decline to respond..... 3

57. **[IF PARENT CARING FOR OWN CHILD CR (Q10=6 or 19 AND CRTYPE=1), ASK]:** {Do/Did} you have plans in place for your [RELATION]’s future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?  
**[IF NOT PARENT CARING FOR OWN CHILD CR (CRTYPE=2 OR (Q10≠6 or 19 AND CRTYPE=1)), ASK]:** {Are/Were} there plans in place for your [RELATION]’s future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?  
 Yes ..... 1  
 No ..... 2  
 Not sure ..... 3
58. **[IF PARENT CARING FOR OWN CHILD CR (Q10=6 or 19 AND CRTYPE=1), ASK]:** {Do/Did} you have plans in place for who {will take/would have taken} care of your [RELATION] if you {are/had been} unable to?  
**[IF NOT PARENT CARING FOR OWN CHILD CR (CRTYPE=2 OR (Q10≠6 or 19 AND CRTYPE=1)), ASK]:** {Are/Were} there plans in place for who {will take/would have taken} care of your [RELATION] if you {are/had been} unable to?  
 Yes ..... 1  
 No ..... 2  
 Not sure ..... 3
59. **[IF PARENT CARING FOR OWN CHILD CR (Q10=6 or 19 AND CRTYPE=1), ASK]:** {Do/Did} you have a plan in place for end-of-life care for your [RELATION]?  
**[IF NOT PARENT CARING FOR OWN CHILD CR (CRTYPE=2 OR (Q10≠6 or 19 AND CRTYPE=1)), ASK]:** {Is/Was} there a plan in place for your [RELATION]’s end-of-life care?  
 Yes ..... 1  
 No ..... 2  
 Not sure ..... 3
60. What {gives/gave} you hope, as a caregiver of someone with a rare condition?  
**[OPEN-ENDED]**
- 

**DEMOGRAPHICS**

Finally, we just have a few basic questions for classification purposes only.

61. {Does/Did} your [RELATION] live in a rural area **[IF PAST CAREGIVER (Q7=2):** at the time you provided care]?  
 Yes ..... 1  
 No ..... 2

62. Are you...
- Male..... 1
  - Female ..... 2
  - Other ..... 3
  - Decline to respond..... 4

63. What is the last grade of school you completed?
- Less than high school ..... 1
  - High school grad/GED..... 2
  - Some college..... 3
  - Technical school or associate’s degree ..... 4
  - College graduate with bachelor’s degree ..... 5
  - Graduate school/ Grad work or professional degree ..... 6

**IF CARING FOR A CHILD THAT LIVES WITH CG (CRTYPE=1 AND Q14=1) AUTOPUNCH Q64=1 AND SKIP TO Q65.**

64. {Are/When you were last caregiving, were} there any children or grandchildren under 18 years old living in your household?
- Yes ..... 1
  - No..... 2
  - Decline to respond..... 3

65. Are you Hispanic or Latino?
- Yes ..... 1
  - No..... 2
  - Decline to respond..... 3

66. Are you...
- Please select all that apply.*
- White ..... 1
  - African-American/Black ..... 2
  - Asian/Pacific Islander ..... 3
  - Native American/Alaskan Native ..... 4
  - Other [SPECIFY \_\_\_\_\_] ..... 5
  - Decline to respond..... 6
  - Hispanic..... 7

67. {What is/At the time of caregiving, what was} your annual household income?

- Under \$15,000 ..... 1
- \$15,000 to \$29,999..... 2
- \$30,000 to \$49,999..... 3
- \$50,000 to \$74,999..... 4
- \$75,000 to \$99,999..... 5
- \$100,000 or more ..... 6
- Decline to respond..... 7

**CLOSE:** Thank you for participating in this important research project. Final results from this study will be released on [www.caregiving.org](http://www.caregiving.org) in early 2018.