

Completing the survey means that you consent to participate in this research study.

Please note that all questions are directed to the person with a rare disease: if you are the parent or caregiver, please answer the questions as the person with a rare disease would answer.

Health care access and service use during the pandemic

1. Were you tested for COVID-19?
 - Yes
 - No

2. If yes to question #1. What was the test result?
 - Positive
 - Negative
 - Inconclusive
 - Don't Know

3. Were you exposed to someone who had COVID-19?
 - Yes
 - No
 - Don't Know

4. Did you have symptoms related to COVID-19?
 - Yes
 - No

5. If answered yes to question 4 What symptoms did you have?
 - New or increased cough
 - Fever greater than 100.5 degrees Fahrenheit (38.0 degrees Celsius)
 - New or increased shortness of breath
 - Sore throat
 - Stuffy nose
 - Runny nose
 - Chest pain
 - Sneezing
 - Wheezing
 - Headache
 - Muscle aches
 - Abdominal pain
 - Vomiting

- Diarrhea
- Loss of taste
- Loss of smell
- Conjunctivitis or pink eye
- Confusion
- Seizures
- Weakness
- Other _____ Free text fill-in

6. For how long did you have these symptoms? (approximate N of days)

7. At the time of completing this survey, have your symptoms resolved?

- Yes
- No
- Never had symptoms

8. Did your rare disease complicate this illness?

- Yes
- No
- Unknown

If yes, how? _____ Free text fill-in

9. Did you experience any worsening of symptoms of your rare disease as a result of this illness? **Check all that apply.**

- New or increased cough
- Fever greater than 100.5 degrees Fahrenheit (38.0 degrees Celsius)
- New or increased shortness of breath
- Sore throat
- Stuffy nose
- Runny nose
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- Sneezing
- Wheezing
- Headache
- Muscle aches
- Abdominal pain
- Vomiting
- Diarrhea
- Loss of taste
- Loss of smell
- Conjunctivitis or pink eye
- Confusion

- Seizures
- Weakness
- Other _____ Free text fill-in

10. After the beginning of the pandemic in the USA (March 2020), were you able to continue seeing your health care provider?

- Yes, without problems
- Yes, but experienced delays in obtaining an appointment
- Yes, but my appointment was done in telemedicine
- No, appointment was put on hold
If not "Yes without problems," please describe the issues or difficulties you had _____ Free text fill-in

11. After the beginning of the pandemic in the USA (March 2020), were you able to continue your treatment?

- Yes, without problems
- Yes, but experienced delays in obtaining treatment
- No, treatment was interrupted
If not "Yes without problems," please describe the issues or difficulties you had _____ Free text fill-in

12. After the beginning of the pandemic in the USA (March 2020), were you able to maintain your diet or access food that is necessary for the treatment of your rare disease?

- Yes, without problems
- Yes, but experienced delays in obtaining treatment
- No, supply of needed food was interrupted and my diet suffered from it
If not "Yes without problems," please describe the issues or difficulties you had _____ Free text fill-in

13. After the beginning of the pandemic in the USA (March 2020), were you able to continue specialized treatment such as occupational therapy or speech therapy?

- Yes, without problems
- Yes, but experienced delays in obtaining treatment
- No, treatment was interrupted
If not "Yes without problems," please describe the issues or difficulties you had _____ Free text fill-in

14. After the beginning of the pandemic in the USA (March 2020), did you experience a medical event for which you would ordinarily be hospitalized, but because of COVID-19 you were managed without hospitalization?

- Yes
- No
- Unknown

If yes, how? _____ Free text fill-in

15. Have stay-at-home orders in your area affected your mood or behavior in a way that requires medical attention?

- Yes
- No
- Unknown

16. Have you or members of your family sought professional support coping with stress or anxiety as a consequence of the COVID-19 pandemic?

- Yes
- No

17. For the parent/caregiver. Did the person you are reporting on pass away?

- Yes
- No

If yes, please report the cause of death (text)

18. Please add below any additional comments or concerns you may have.

Free text _____

*Questions #1-18 have been re-numbered and are listed as questions 8.1 – 8.16 in the original survey