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.**

## Symptoms and Diagnosis

**CHANGES AFTER THE BEGINNING OF THE COVID-19 PANDEMIC IN THE USA**

1. Did you acquire COVID-19?
   - ○ Yes
   - ○ No
   - ○ Don't Know

**You answered that you acquired the COVID-19 infection.**

2. When were you diagnosed with COVID-19? Month/Year

3. How was the diagnosis of COVID-19 made?
   Specific testing
   Symptoms
   Exposure to COVID-19

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
- ○ No symptoms

5. For how long did you have symptoms due to COVID-19? (approximate N of days)

6. At the time of completing this survey, have your COVID-19 symptoms resolved?
   - ○ Yes
   - ○ No
   - ○ Never had symptoms

7. Did your rare disease complicate COVID-19?

   - ○ Yes
   - ○ No
   - ○ Unknown

   If yes, how? _____Free text fill-in

8. Did you experience any worsening of symptoms of your rare disease as a result of COVID-19? **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
   - ○ 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
- ○ No symptoms

9. After the diagnosis of COVID-19, 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 you had _____ Free text fill-in

10. After the diagnosis of COVID-19, 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

11. After the diagnosis of COVID-19, were you able to maintain your diet or access food that is necessary for the treatment of your rare disease during the pandemic?
    - ○ Yes, without problems
    - ○ Yes, but experienced delays/problems
    - ○ No, supply of needed food was interrupted and my diet suffered from it

    If not, “Yes without problems,” please tell us about your complaints _____ Free text fill-in

12. After the diagnosis of COVID-19, 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

13. After the diagnosis of COVID-19, 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

14. Have stay-at-home orders in your area affected your mood or behavior in a way that requires medical attention?
    - ○ Yes
    - ○ No
    - ○ Unknown

15. 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

16. Did you receive investigational drugs to treat COVID-19 or participate in a clinical trial?
    - ○ Yes
    - ○ No
    - ○ Unknown

    If yes, was the person treated with:
    - ○ Chloroquine
    - ○ Hydroxychloroquine
    - ○ Oseltamivir (Tamiflul)
    - ○ Remdesivir
    - ○ Lopinavir-ritonavir
    - ○ Azithromycin (specifically for COVID-19)
    - ○ Oral or intraveneous corticosteroids (specifically for COVID-19)
    - ○ Other medication: specify _____

17. Were you seen in an emergency department or urgent care center?
    - ○ Yes
    - ○ No
    - ○ Unknown

18. Were you hospitalized?
    - ○ Yes
    - ○ No
    - ○ Unknown

19. Did you require supplemental oxygen?
    - ○ Yes
    - ○ No

- ○ Unknown

20. Did you require intubation and mechanical ventilation?
    - ○ Yes
    - ○ No
    - ○ Unknown

21. For the parent/caregiver: Did the person you are reporting on pass away?
    - ○ Yes
    - ○ No

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

22. Please add below any additional comments or concerns you may have.
    Free text _____

**Questions 1 – 22 have been renumbered and are listed as questions 5.1 and 7.1 – 7.21 on the original survey*