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.

1. Please answer the following initial eligibility questions:

1.1 Do you live in the USA? (y/n, if No -decline)

1.2 Are you:

a. A person with a rare disease?

b. The parent/caregiver for a child under 18-years of age who lives with a rare disease?

c. The parent/caregiver of a person with a rare disease who needs assistance with filling out the survey?

(If none of the above, decline)

1.3 Are you under 90 years of age?

(y/n, If Yes-decline)

1.4 Please type your disease in the field below: as you type, the system will show you options that may help you find the right diagnosis

1.5 Are you (or your child) participating in a clinical research project that studies your specific disease, or have done so in the past?

1.6 Can you name the center where the research is (was) conducted? (Y/N/DK, if Yes, list)

1.7 Is (was) the center part of a RDCRN consortium? (Y/N/DK, Drop-down menu of all consortia to help)

Thank you. Please answer the consent questions below:

2.1 I agree to provide contact information so that I can participate in a follow-up survey, have my survey answers linked to RDCRN records, and learn about opportunities to participate in research studies conducted by the RDCRN.

2.2 I do not agree to provide my contact information, but would like to participate in the survey. I understand that by not providing the contact information, I cannot participate in a follow-up survey and the RDCRN cannot contact me in the future to let me know about new studies. (Answer to 2.2 can be yes only if answer to 2.1 is No).

2. CONTACT INFORMATION. (This section will appear only when the participant provides the appropriate consent).

3.1 Name of person with rare disease:

3.2 Date of birth of person with rare disease

3.3 Name of reporter and relationship with person:

How would you like to be contacted? Please provide all information that you are comfortable sharing:

3.4 By telephone: area code phone number

3.5 By email: email address

3.6 By regular mail: street address/apartment number/ city / state / ZIP code

3. **GENERAL QUESTIONS**

4.1 State of residence: (Dropdown containing US states)

4.2 What is your age? (yrs):

4.3 What is your gender? (Dropdown)
Male
Female
Other
Choose not to answer

4.4 What is your race? (Dropdown)
White
Black or African American
American Indian or Native Alaskan
Asian
Native Hawaiian or Pacific Islander
Other
Choose not to answer

4.7 What is your ethnicity? (Dropdown)
Hispanic/Latino
Non-Hispanic or Latino
Unknown
Choose not to answer

4.8 Please check if you had any of the following symptoms before the COVID-19 pandemic began in the USA. Think about your symptoms in January-February 2020. Check all that apply. Did anything change after the beginning of the pandemic (March 2020)? Dropdown containing various symptoms. Columns indicating Before the pandemic (Y/N) and After the beginning of the pandemic (Y/N/less severe/more severe)

No symptoms
Blood and Bleeding: blood clots, easy bruising, anemia (low blood cell count), blood in stool, black stools, coughing or vomiting up blood, lip or mouth bleeding, nosebleeds
Breathing: cough, wheezing, difficulty breathing, chest pain
Cardiac: heart failure, racing heartbeat, arrhythmia
Digestive: vomiting, nausea, abdominal pain, bloating, diarrhea, food impaction (getting stuck in the swallowing tube), poor weight gain, weight loss, difficulty swallowing
Ear, Nose and Throat: difficulty swallowing, nasal congestion, nasal drainage, ear pain, hearing loss
Endocrine: Diabetes, thyroid disease, adrenal insufficiency, hypocalcemia (low calcium in blood), hypoglycemia (low blood sugar), other—specify _____
Immune defects: active infections (bacterial, viral, mycobacterial), abnormal function or amount of white blood cells, recurrent infections (urinary, respiratory, skin)
Musculoskeletal: Scoliosis > 30 degrees, Unable to walk more than 50 feet
Neurological and Behavioral: headache, migraine, seizures (febrile or other), autism, slurred speech, difficulty swallowing, weakness, tremors, coma, incoordination, intellectual disabilities, cognitive or behavioral impairment, confusion, combativeness, hallucinations
Kidney: renal failure, discolored urine
Skin: Rash, itching
Rheumatological: joint pain or swelling, muscle aches, dry mouth
Allergies: anaphylaxis, eczema, hayfever, hives

4.9 Please check if you used any of the treatments before the COVID-19 pandemic began in the USA. Think about the medications you took or treatments you routinely received in January-February 2020. Check all that apply. Did anything change after the beginning of the pandemic (March 2020)? Dropdown containing various medications. Columns indicating Before the pandemic (Y/N) and After the beginning of the pandemic (Y/N/lower dosage/higher dosage)

No medications
Antibiotics: azithromycin (Zithromax), doxycycline, minocycline, other oral antibiotics, inhaled antibiotics (TOBI, Cayston, Colistin), intravenous antibiotics, other _____
Anticlotting drugs: warfarin (Coumadin), enoxaparin (Lovenox) injections, other _____
Biological agents: antolibumab, rituximab (Rituxan, MabThera, Truxima), benralizumab (Fasenra), dupilumab (Dupixent), eculizumab (Soliris), mepolizumab (Nucala), reslizumab (Cinqair), bevacizumab (Avastin, Zirabev, MVasi), other _____
Bone loss prevention drugs: Bisphosphonates, other_____
Blood transfusions
Breathing drugs: inhaled albuterol (Ventolin, Proair), inhaled corticosteroids (Pulmicort, Qvar, Flovent, Advair, Symbacort), ipratropium (Atrovent), tiotropium (Spiriva), hypertonic saline (HyperSal), other _____
Breathing therapies: home supplemental oxygen, airway clearance techniques (percussion vest, Acapella device, conventional chest physiotherapy), continuous positive airway pressure support (CPAP), bilevel positive airway pressure support (BiPAP), other _____
Cardiac and blood pressure: lisinopril (Prinivil, Zestril, Qbrelis), captopril, enalapril, other _____

Digestive drugs: proton pump inhibitors [omeprazole (Prilosec), lansoprazole (Prevacid), pantoprazole (Protonix), rabeprazole (Aciphex), dexlansoprazole (Dexilen)], other _____
Immunoglobulin infusions (intravenous or subcutaneous injections), other _____
Immune suppressants: azathioprine (Imuran), mycophenolate (CellCept, Myfortic), tacrolimus (Prograf), Sirolimus (Rapamune), everolimus (Afinitor)
Steroids: oral corticosteroids (prednisone), topical swallowed steroids (fluticasone), nonabsorbable oral steroids (budesonide), nasal topical steroids, other _____
Neurological: oral anticonvulsants, vigabatrin (Sabril), levetiracetam (Keppra), lamotrigine (Lamictal), clonazepam (Klonopin), clobazam (Onfi), divalproex/valproic acid (Depakote), Riluzole (Rilutek), Edaravone (Radicava, Radicut), dextromethorphan/quinidine (Nuedexta), baclofen, tizanidine (Zanaflex), other _____
Other drugs: pyridostigmine (Mestinon), acetazolamide (Diamox), D-galactose, mannose, glycerolphenylbutyrate, sodium phenylbutyrate, sodium benzoate, arginine, citrulline, coenzyme Q10/ubiquinol, oral iron supplement, tranexamic acid, ibuprofen (Advil), naproxen (Aleve), aspirin, other non-steroidal anti-inflammatory drugs, other _____
Diet: tube feeding, intravenous nutrition, special diet, elemental diet, food elimination diet, other _____

4.10 Do you have other diseases or complications related to the rare disease? (Yes/No)
If yes, what?
(Dropdown containing the following)
Coronary artery disease, congenital heart disease, heart failure, heterotaxy, hypertension, other heart diseases
Diabetes
Hypothyroidism
Adrenal Insufficiency
Growth Hormone Failure
Asthma, chronic obstructive pulmonary disease (COPD), other chronic lung disease
Cancer or malignancy. If yes, type _____ Free-text fill-in blanks or Dropdown
History of stroke
Seizures or epilepsy
Intellectual or developmental disabilities
Lack of ability to communicate
Motor weakness or impairment
Spasticity
Dystonia
Chronic bleeding from stomach and/or bowels
Reflux
Delayed gastric emptying
Intestinal motility issues
Chronic anemia
Inflammatory bowel disease (Crohn disease, ulcerative colitis, gluten intolerance, other)
Gastric or intestinal polyps
Chronic kidney disease
Chronic liver disease
Glaucoma

Eczema
History of transplantation. If yes, type _____ Free-text fill-in blanks or Dropdown
Vascular malformations. If yes, specify type and location (lung, liver, brain, stomach, small bowel, large bowel (colon), eye)
Other diseases or complications _____

4.11 Please check if you experienced any of the following symptoms before the COVID-19 pandemic began in the USA. Think about your January-February 2020. Check all that apply. (Dropdown)
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
Muscles aches
Loss of taste
Loss of smell
Conjunctivitis or pink eye
Confusion
Seizures
Weakness
Other _____ Free text fill-in

4.12 If you experienced COVID-19 symptoms after the beginning of the pandemic in the USA, have you been able to get advice from a health care provider about the opportunity to be tested for COVID-19? (Y/N)

4.13 Do you smoke tobacco cigarettes? Dropdown Yes No Unknown

4.14 Do you currently use other tobacco products? Dropdown Yes No Unknown

4.15 Do you currently use electronic cigarettes or vape? Dropdown Yes No Unknown

4.16 Do you currently smoke marijuana or use THC-containing products? Dropdown Yes No Unknown

4.17 Do you use psychoactive drugs not prescribed by a physician? Dropdown Yes No Unknown

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

5.1 Did you acquire COVID-19? Dropdown (Yes/ No/Don't know)
(Skip pattern: if No, continue with section 6 below; If Yes, hide Sections 6 and 8 and jump to Section 7, COVID-19 specific questions; If DK, hide Sections 6 and 7 and jump to Section 8)

6 You answered that you did not acquire the COVID-19 infection.

6.1 Did you have any of the following symptoms? (Dropdown)
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
Muscles aches
Loss of taste
Loss of smell
Conjunctivitis or pink eye
Confusion
Seizures
Weakness
Other _____ Free text fill-in

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

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

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

6.5 Were you able to maintain your diet or access food that is necessary for the treatment of your rare disease during the U.S. pandemic?
(Dropdown : Yes, without problems // Yes, but experienced delays/problems //No, supply of needed food was interrupted and my diet suffered from it)

f not “Yes without problems,” please describe the issues or difficulties you had _____ Free text fill-in

6.6 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?
(Dropdown: 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

6.7 Did you experience a medical event for which you would ordinarily be hospitalized, but because of COVID-19 you were managed without hospitalization? Dropdown Yes No Unknown
If yes, how? _____ Free text fill-in

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

6.9 Have you or members of your family sought professional support coping with stress or anxiety as a consequence of the COVID-19 pandemic? (Y/N)

6.10 For the parent/caregiver: Did the person you are reporting on pass away? (Dropdown :Yes/ No)
If yes, please report the cause of death (text)
Thank you for participating in this important interview. We will post results of this survey as people like you respond, find aggregate survey results on the website of the RDCRN: RDCRN.ORG

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

Free text_____

STOP INTERVIEW FOR THOSE WHO ANSWERED THAT THEY DID NOT ACQUIRE COVID-19.

7 RESUME HERE INTERVIEW FOR THOSE WHO ANSWERED THAT THEY ACQUIRED COVID-19.

You answered that you acquired the COVID-19 infection.

7.1 When were you diagnosed with COVID-19? Mo/year

7.2 How was the diagnosis of COVID-19 made? Dropdown Specific testing Symptoms Exposure to COVID-19

7.3 What symptoms did you have? Dropdown
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
Muscles 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

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

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

7.6 Did your rare disease complicate COVID-19? Dropdown Yes No Unknown
If yes, how? _____ Free text fill-in

7.7 Did you experience any worsening of symptoms of your rare disease as a result of COVID-19? Dropdown list of symptoms as for general question – check all that apply

7.8 After the diagnosis of COVID-19, were you able to continue seeing your health care provider? (Dropdown: 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

7.9 After the diagnosis of COVID-19, were you able to continue your treatment?
(Dropdown: 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

7.10 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?
(Dropdown: 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 problem, Please tell us about your complaints _____ Free text fill-in

7.11 After the diagnosis of COVID-19, were you able to continue specialized treatment such as occupational therapy or speech therapy?
(Dropdown: 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

7.12 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?
Dropdown Yes No Unknown
If yes, how? _____ Free text fill-in

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

7.14 Have you or members of your family sought professional support coping with stress or anxiety as a consequence of the COVID-19 pandemic? (Y/N)

7.15 Did you receive investigational drugs to treat COVID-19 or participate in a clinical trial?
Dropdown Yes No Unknown
If yes, was the person treated with: Dropdown
Chloroquine
Hydroxychloroquine
Oseltamivir (Tamiflu)
Remdesivir
Lopinavir-ritonavir
Azithromycin (specifically for COVID-19)
Oral or intravenous corticosteroids (specifically for COVID-19)
Other medication: specify_____

7.16 Were you seen in an emergency department or urgent care center? Dropdown Yes No Unknown

7.17 Were you hospitalized? Dropdown Yes No Unknown

7.18 Did you require supplemental oxygen? Dropdown Yes No Unknown

7.19 Did you require intubation and mechanical ventilation? Dropdown Yes No Unknown

7.20 For the parent/caregiver: Did the person you are reporting on pass away? (Yes/ No)
If yes, please report the cause of death (text)
Thank you for participating in this important interview. We will post results of this survey as people like you respond, find aggregate survey results on the website of the RDCRN: RDCRN.ORG

7.21 Please add below any additional comments or concerns you may have.
Free text_____

STOP INTERVIEW FOR THOSE WHO ANSWERED THAT THEY ACQUIRED COVID-19.

8. RESUME HERE INTERVIEW FOR THOSE WHO ANSWERED THAT THEY DID NOT KNOW IF THEY HAD COVID-19.

You answered that you do not know if you acquired COVID-19 infection.

8.1 Were you tested for COVID-19? Yes No
If yes to 8.1: What was the test result? Positive/Negative/Inconclusive/Don't Know

8.2 Were you exposed to someone who had COVID-19? Y/N/DK

8.3 Did you have symptoms related to COVID-19? Y/N
If answered Yes to 8.3 What symptoms did you have? Dropdown
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
Muscles aches
Abdominal pain
Vomiting
Diarrhea
Loss of taste
Loss of smell
Conjunctivitis or pink eye
Confusion
Seizures
Weakness
Other _____ Free text fill-in

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

8.5 At the time of completing this survey, have your symptoms resolved? Dropdown Yes No Never had symptoms

8.6 Did your rare disease complicate this illness? Yes No Unknown
If yes, how? _____ Free text fill-in

8.7 Did you experience any worsening of symptoms of your rare disease as a result of this illness?
Dropdown list of symptoms as for general question – check all that apply

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

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

8.10 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?
(Dropdown: 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 describe the issues or difficulties you had _____ Free text fill-in

8.11 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?
(Dropdown: 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

8.12 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?
Dropdown Yes No Unknown
If yes, how? _____ Free text fill-in

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

Dropdown Yes No Unknown

8.14 Have you or members of your family sought professional support coping with stress or anxiety as a consequence of the COVID-19 pandemic? (Y/N)

8.15 For the parent/caregiver: Did the person you are reporting on pass away? (Dropdown :Yes/ No)
If yes, please report the cause of death (text)

Thank you for participating in this important interview. We will post results of this survey as people like you respond, find aggregate survey results on the website of the RDCRN: RDCRN.ORG

8.16 Please add below any additional comments or concerns you may have.
Free text_____

STOP INTERVIEW FOR THOSE WHO ANSWERED THAT THEY DID NOT KNOW IF THEY HAD COVID-19