



Instructions

Thank you for taking the time to enroll with the CoRDS Registry. This questionnaire:

- Takes 10 - 20 minutes to complete
- Will refer to the person with the rare or unknown diagnosis as **“the participant”**
- Can be updated at any time by logging in to the CoRDS online portal or by contacting CoRDS personnel

CoRDS personnel will contact you annually to update your questionnaire.

If you have any questions while completing this form, please contact CoRDS at (877) 658 – 9192 during business hours, 8:30am-5:00pm (CST) Monday through Friday. If you need assistance after business hours, please leave a message or email cords@sanfordhealth.org.

*For accurate data curation, please remember to write legibly. Thank you.

1. Today's Date (MM/DD/YYYY):

2. Who is completing this questionnaire?

I am enrolling myself (You must be over the age of 18 to provide information for the registry)

I am enrolling my child (You must be the participant's parent or legal guardian to provide information for the registry)

I am enrolling an adult who is not cognitively able to enroll (You must be the participant's legally authorized representative (LAR) to provide information for the registry)

Permissions & Data Sharing

By participating in CoRDS, your de-identified information will be shared with researchers who access the CoRDS Registry. Below are options that allow you to share your data with other entities. In the following questions, please select how you want your data shared. Please complete this section before moving on.

3. I give permission to CoRDS to contact me about participating in future research studies:

Yes

No

Don't know

4. I give permission to CoRDS to contact me about donating a sample of blood, tissue, or other biospecimen for research in the future:

Yes

No

Don't know

5. I give permission to CoRDS to provide a subset of de-identified information to other databases collecting information on rare diseases in order to avoid a duplication of efforts and to increase knowledge:

Yes

No

Don't know

Participant Information

6. First Name:	
7. Middle Name:	
8. Last Name:	
<input type="checkbox"/> Check if the legal given name (as per birth certificate) of the participant is the same as indicated above	
Legal given name of the participant (as per birth certificate)	
9. First Name:	
10. Middle Name:	
11. Last Name:	
12. Date of Birth:	
13. City, Town, or Village of Birth:	
14. Country of Birth:	
15. Current Address 1:	
16. Current Address 2:	
17. Current City, Town, or Village:	18. Current State or Province:
19. Zip/Postal Code	20. Country
21. Email Address:	
22. Primary Telephone Number:	
Parent/Legally Authorized Representative (LAR) Information	
Please complete this section if you are the participant's parent/guardian (participant must be under the age of 18) or legally authorized representative (participant is not cognitively able to enroll).	
23. First Name:	
24. Middle Name:	
25. Last Name:	
26. Primary Telephone Number:	
27. Email Address:	
<input type="checkbox"/> Check if the address is the same as the participant's, then skip to the next section	

28. Address 1:	
29. Address 2:	
30. City, Town, or Village	31. State or Province
32. Zip/Postal Code:	33. Country
34. Relationship to Secondary Contact:	
<input type="checkbox"/> Family Member	<input type="checkbox"/> Spouse/Partner
<input type="checkbox"/> Friend	<input type="checkbox"/> Other
35. If you selected "other" above, please specify: _____	
36. First Name:	
37. Middle Name:	
38. Last Name:	
39. Primary Telephone Number:	
40. Email Address:	
<input type="checkbox"/> Check if the address is the same as the participant's above, then skip to the next section	
41. Address 1:	
42. Address 2:	
43. City, Town or Village	
44. State or Province	
45. Zip/Postal Code	46. Country
Enrollment, Contact & Communication Preferences	
47. Special Communication Needs: Do you (the person completing this form) have any special communication needs? Please select all that apply, or describe in the space provided.	
<input type="checkbox"/> No special needs – both spoken and written language are acceptable	<input type="checkbox"/> Written language preferred
<input type="checkbox"/> Sign language required	<input type="checkbox"/> Other

<input type="checkbox"/> Spoken language preferred				
48. If you selected "other" above, please specify: _____				
Participant Socio-demographic Information				
Please provide information about the participant's background and diagnosis in the following sections.				
49. Sex:				
<input type="checkbox"/> Female	<input type="checkbox"/> Male	<input type="checkbox"/> Intersex	<input type="checkbox"/> Unknown	<input type="checkbox"/> Other
50. Sex at Birth:				
<input type="checkbox"/> Female	<input type="checkbox"/> Male	<input type="checkbox"/> Intersex	<input type="checkbox"/> Unknown	<input type="checkbox"/> Other
51. Race:				
<input type="checkbox"/> American Indian or Alaska Native		<input type="checkbox"/> Black or African American		
<input type="checkbox"/> Asian – Asian Indian		<input type="checkbox"/> Pacific Islander – Native Hawaiian		
<input type="checkbox"/> Asian – Chinese		<input type="checkbox"/> Pacific Islander – Guamanian		
<input type="checkbox"/> Asian – Filipino		<input type="checkbox"/> Pacific Islander – Chamorro		
<input type="checkbox"/> Asian - Japanese		<input type="checkbox"/> Pacific Islander – Samoan		
<input type="checkbox"/> Asian – Korean		<input type="checkbox"/> Pacific Islander – Other Pacific Islander		
<input type="checkbox"/> Asian – Vietnamese		<input type="checkbox"/> White		
<input type="checkbox"/> Asian – Other Asian		<input type="checkbox"/> Other/Unknown/Refuse to Answer		
52. Ethnicity:				
<input type="checkbox"/> Not Hispanic or Latino		<input type="checkbox"/> Hispanic or Latino – Puerto Rican		
<input type="checkbox"/> Ashkenazi Jewish		<input type="checkbox"/> Hispanic or Latino – South American		
<input type="checkbox"/> French Canadian		<input type="checkbox"/> Hispanic or Latino – Other Latin American		
<input type="checkbox"/> Hispanic or Latino – Central American		<input type="checkbox"/> Hispanic or Latino – Other Hispanic/Latino/Spanish		

<input type="checkbox"/> Hispanic or Latino – Cuban	<input type="checkbox"/> Unknown/No answer	
<input type="checkbox"/> Hispanic or Latino – Dominican (Republican)	<input type="checkbox"/> Other	
<input type="checkbox"/> Hispanic or Latino - Mexican		
53. If you selected “other” above, please specify: _____		
54. Is the participant still living?		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	
55. If you selected “no” above, please indicate date of death (MM/DD/YYYY): _____		
Cause of death:		
Diagnosis		
56. For genetic rare diseases, is the participant an unaffected carrier of the rare disease?		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
57. If you selected “yes” above, please list the rare disease for which the participant is a carrier for.		
58. Rare Disease Diagnosis: Please list all rare disease diagnoses.		
Please complete the questions below in relation to the disease identified above. If you have more than one rare disease, please answer questions 58 and 61 – 68 for each condition.		
59. Rare Disease Symptoms: Please list symptoms of rare disease diagnosis. Separate with commas.		
60. Undiagnosed: If no clinical diagnosis has been made, please list symptoms. Separate with commas.		

61. Other Diagnoses: Please list non-rare diagnosis. Separate with commas.

62. Age at Diagnosis:

Prenatal

Unknown

At birth

N/A

Age

63. If you selected "age" above, please indicate age:

_____ Days(s)

_____ Week(s)

_____ Month(s)

_____ Year(s)

64. Age at first symptom:

Prenatal

Unknown

At birth

N/A

Age

65. If you selected "age" above, please indicate age:

_____ Days(s)

_____ Week(s)

_____ Month(s)

_____ Year(s)

66. How was the rare diagnosis determined? Select all that apply.

Genetic Laboratory Analysis

Newborn Screening

Histology

Physical Examination

Imaging - CT

Unknown

Imaging - MRI

Other

Imaging – PET

67. If you selected "other" above, please specify:

68. Where was the diagnosis made?

Hospital / Institution:

City:

State or Province:

Country:

Family History

69. Which family members also have the participant's rare disease? Select all that apply.

<input type="checkbox"/> None	<input type="checkbox"/> Unknown
<input type="checkbox"/> Mother	<input type="checkbox"/> Paternal Grandmother
<input type="checkbox"/> Father	<input type="checkbox"/> Maternal Aunt
<input type="checkbox"/> Brother	<input type="checkbox"/> Paternal Aunt
<input type="checkbox"/> Half - brother	<input type="checkbox"/> Maternal Uncle
<input type="checkbox"/> Sister	<input type="checkbox"/> Paternal Uncle
<input type="checkbox"/> Half – sister	<input type="checkbox"/> Maternal Cousin
<input type="checkbox"/> Daughter	<input type="checkbox"/> Paternal Cousin
<input type="checkbox"/> Son	<input type="checkbox"/> Granddaughter
<input type="checkbox"/> Maternal Grandfather	<input type="checkbox"/> Grandson
<input type="checkbox"/> Paternal Grandfather	<input type="checkbox"/> Niece
<input type="checkbox"/> Maternal Grandmother	<input type="checkbox"/> Nephew

Quality of Life

70. In general, would the participant say his/her health is...

<input type="checkbox"/> Excellent	<input type="checkbox"/> Very good	<input type="checkbox"/> Good	<input type="checkbox"/> Fair	<input type="checkbox"/> Poor
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71. Does the participant's health now limit him/her in doing vigorous activities?

<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Often	<input type="checkbox"/> Always
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72. How much did pain interfere with the participant's enjoyment of life?

<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Often	<input type="checkbox"/> Always
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73. How often does the participant feel tired?

<input type="checkbox"/> Never	<input type="checkbox"/> Rarely	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Often	<input type="checkbox"/> Always
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74. The participant feels depressed... Never Rarely Sometimes Often Always**Clinical Research Participation & Biospecimens****75. Has the participant *previously participated in any clinical trials* related to their rare disease?** Yes No Don't know**76. Does the participant *currently participate in any clinical trials* related to their rare disease?** Yes No Don't know**77. Has the participant *previously donated a sample of blood, tissue, or other biospecimen* for research?** Yes No Don't know**78. If Yes:**

Type of biospecimen:

 Blood Tissue Other bodily fluid Urine Saliva/Cheek Swab Unknown**79. Location of biospecimen donation:** Check here if location unknown**Hospital / Institution****City:****State or Province:****Country:****Thank you for your participation!****Questions?****CoRDS Personnel**

Sanford Research

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