CoRDS Registry

Coordination of Rare Diseases at Sanford

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 no 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:	
☐ 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:	
☐ 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:	
☐ Family Member	☐ Spouse/Partner
☐ Friend	☐ 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:	
☐ Check if the address is the same as he 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.	
☐ No special needs – both spoken and written language are acceptable	☐ Written language preferred
☐ Sign language required	☐ Other

☐ 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:

☐ Female	☐ Male	☐ Intersex	☐ Unknown	☐ Other

50. Sex at Birth:

☐ Female	☐ Male	☐ Intersex	☐ Unknown	☐ Other

51. Race:

☐ American Indian or Alaska Native	☐ Black or African American
☐ Asian – Asian Indian	☐ Pacific Islander – Native Hawaiian
☐ Asian – Chinese	☐ Pacific Islander – Guamanian
☐ Asian – Filipino	☐ Pacific Islander – Chamorro
☐ Asian - Japanese	☐ Pacific Islander – Samoan
☐ Asian – Korean	☐ Pacific Islander – Other Pacific Islander
☐ Asian – Vietnamese	☐ White
☐ Asian – Other Asian	☐ Other/Unknown/Refuse to Answer

52. Ethnicity:

☐ Not Hispanic or Latino	☐ Hispanic or Latino – Puerto Rican
☐ Ashkenazi Jewish	☐ Hispanic or Latino – South American
☐ French Canadian	☐ Hispanic or Latino – Other Latin American
☐ Hispanic or Latino – Central American	☐ Hispanic or Latino – Other Hispanic/Latino/Spanish

☐ Hispanic or Latino – Cuban	☐ Unknown/No answer
☐ Hispanic or Latino – Dominican (Republican)	☐ Other
☐ Hispanic or Latino - Mexican	
53. If you selected "other" above, please specify: ___________________________	
54. Is the participant still living?	
☐ Yes	☐ 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?		
☐ Yes	☐ No	☐ 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.

☐ None	☐ Unknown
☐ Mother	☐ Paternal Grandmother
☐ Father	☐ Maternal Aunt
☐ Brother	☐ Paternal Aunt
☐ Half - brother	☐ Maternal Uncle
☐ Sister	☐ Paternal Uncle
☐ Half – sister	☐ Maternal Cousin
☐ Daughter	☐ Paternal Cousin
☐ Son	☐ Granddaughter
☐ Maternal Grandfather	☐ Grandson
☐ Paternal Grandfather	☐ Niece
☐ Maternal Grandmother	☐ Nephew

Quality of Life

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

☐ Excellent	☐ Very good	☐ Good	☐ Fair	☐ Poor

71. Does the participant's health now limit him/her in doing vigorous activities?

☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

72. How much did pain interfere with the participant's enjoyment of life?

☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

73. How often does the participant feel tired?

☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

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
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Sioux Falls, South Dakota 57104
Phone (toll-free): 1 (877) 658-9192
Email: CoRDS@sanfordhealth.org