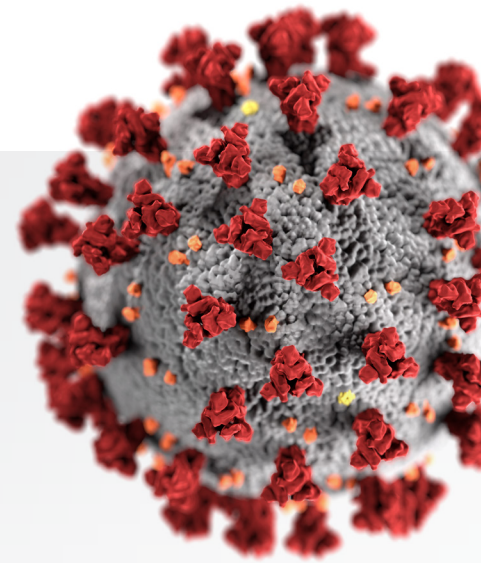


Research survey for rare disease patients and their families about impacts of COVID-19



Complete a 20-minute online survey from home

Why are we doing this research?

The novel coronavirus pandemic is impacting people with rare diseases and their families. Those impacts can be related to physical health, emotional health, availability of supplies, access to care, or other problems. Your responses may help researchers understand the impacts of COVID-19 on the rare disease community.

Who can participate?

You qualify for this study if you or someone you care for has been diagnosed with a rare disease, is 0 to 89 years old, and currently lives in the United States. A rare disease is defined as a condition that affects fewer than 200,000 people. The NIH's NCATS **Genetic and Rare Diseases Information Center** (GARD) offers information on nearly 7,000 rare diseases.

Will you or your child be paid?

Participants will not receive payment for completing this survey.

What will happen in this study?

You will be asked to share your experience by completing our survey. Some things we hope to learn:

- Who is becoming infected?
- Where do they live?
- What symptoms are they seeing?
- What treatments are they receiving?
- How is access to care changing?
- Are patients able to obtain needed medical and nutritional supplies?
- How are stress and anxiety impacting patients and families?

To complete the survey or learn more:

 RareDiseasesNetwork.org/COVIDsurvey

Questions?

Email the study team at rd.covid19@cchmc.org