

AWaRDS Study

Adults with **Rare Disorders** Support Study



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What is the study about?

In partnership with the National Organization for Rare Disorders, this will be the first large-scale study about the information and psychosocial support needs of people living with rare disorders. The purpose of this research study is to assess these needs, from the perspectives of people with a variety of rare disorders, to find similarities and differences across disorders. To ensure that results reflect the diversity of the rare disease community, it is crucial that as many people living with a rare disease as possible take part.

What would I do as a study participant?

There are two ways to participate.

1. You can follow this link, www.bit.ly/2hWZLr2 to take a 40-minute online survey about your experiences with and information and support needs related to your rare disorder (paper forms are available by request). If it is physically difficult to respond, someone may enter your responses for you.
2. During the survey, you can opt to sign up for a second study, which involves an online focus group about the information and psychosocial support needs with others with rare disorders. You must participate in the survey in order to be eligible for the focus group, but the focus group study is not required to participate in the survey. You will be paid \$20 for participating in the focus group.

Who is eligible to participate?

You must be an adult or the age of majority in your state, be able to communicate in English, and have a rare disease or disorder or undiagnosed rare condition. Caregivers who do not have a rare disorder themselves are NOT eligible to participate at this time. A disease is generally considered rare if it affects fewer than 200,000 affected individuals in the United States or fewer than 1 in 2,000 in Europe. A list of rare diseases can be found here: www.rarediseases.info.nih.gov/diseases/browse-by-first-letter. Because rare disorders are discovered and prevalence estimates change frequently, you may participate even if your disorder does not appear on the list.

What will we do with study findings?

We will send a summary of results to all participants. To help NORD, rare disorder organizations, and healthcare professionals meet the needs of people with rare disorders, results will be shared through reports, conference presentations, scientific publications.

Who are the researchers?



Kathleen Bogart, PhD, Principal Investigator, Assistant Professor of Psychology at Oregon State University, studies psychosocial needs of people with rare disorders and has a rare disorder herself. She also serves on the Board of Directors of a NORD member organization. Contact her at kathleen.bogart@oregonstate.edu or 541-737-1357.



Veronica Irvin, PhD, MPH, Co-Investigator, is Assistant Professor of Public Health at OSU. She has experience analyzing information offered by support organizations.