

# RESEARCH PARTICIPATION STEPS

step



## Sign up online and consent



Estimated time to complete this step:  
15-20 minutes



### Why is it important to register with Simons Searchlight and participate in research?

Joining Simons Searchlight connects you with other families, advances research on CUL3, and empowers you with valuable knowledge. Your unique journey contributes to discoveries that can accelerate new treatments and improve lives worldwide.

Register Today: [SimonsSearchlight.org](https://SimonsSearchlight.org)

## RESEARCH PARTICIPATION STEPS

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### Upload your genetic lab report



Estimated time to complete this step:  
5 minutes



#### Why is it important to upload your genetic lab report?

Share your genetic lab report to help researchers learn more about CUL3.

Don't have your report? Simons Searchlight can help!  
[bit.ly/Genetics\\_Lab\\_Report\\_FAQ](https://bit.ly/Genetics_Lab_Report_FAQ)

Complete this Step: [bit.ly/Simons\\_Searchlight\\_Dashboard](https://bit.ly/Simons_Searchlight_Dashboard)

# RESEARCH PARTICIPATION STEPS

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## Share your medical history



Estimated time to complete this step:  
30-60 minutes



### Why is sharing medical history important?

This is the first survey we ask you to complete after registration because it contains some of the most important data researchers need. It helps them understand how CUL3 affects daily life over time, guiding future treatments and support.

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# RESEARCH PARTICIPATION STEPS

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## Fill out surveys



**Estimated time to complete this step:**  
1-3 hours, depending on size of family

**Why is it important to complete all research surveys in Simons Searchlight?**

Completing all assigned surveys on development, behavior, and more helps researchers understand CUL3.

You will fill these out after you share your medical history.

**Plus, you earn a digital gift card as a thank-you!**

**Complete this Step: [bit.ly/Simons\\_Searchlight\\_Dashboard](https://bit.ly/Simons_Searchlight_Dashboard)**

## RESEARCH PARTICIPATION STEPS

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### Provide an optional blood sample



Estimated time to complete this step:  
30 minutes



Why is submitting a blood sample important for Simons Searchlight and the research community?

Contributing a one-time blood sample supports research resources like DNA and cell lines. Blood donation through Quest is currently available only to U.S. participants. **Non-U.S. families with questions are welcome to reach out to us at [Coordinator@SimonsSearchlight.org](mailto:Coordinator@SimonsSearchlight.org)—we're happy to help!**

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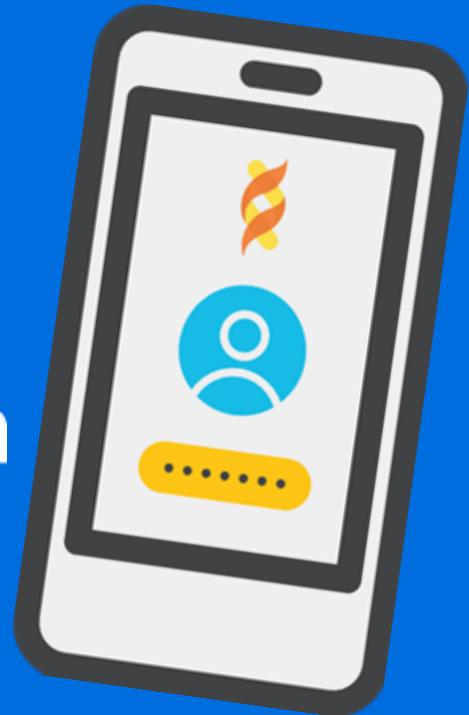
# RESEARCH PARTICIPATION STEPS

step

## Update Simons Searchlight every year and continue your participation



Estimated time to complete this step:  
1 hour



Why is it important to stay in touch and update Simons Searchlight every year?

Keep Simons Searchlight updated each year with any new insights. Your ongoing participation, including completing annual surveys strengthens research on CUL3 and provides invaluable data over time.

Complete this Step: [bit.ly/Simons\\_Searchlight\\_Dashboard](https://bit.ly/Simons_Searchlight_Dashboard)