

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

SIMONS
SEARCHLIGHT



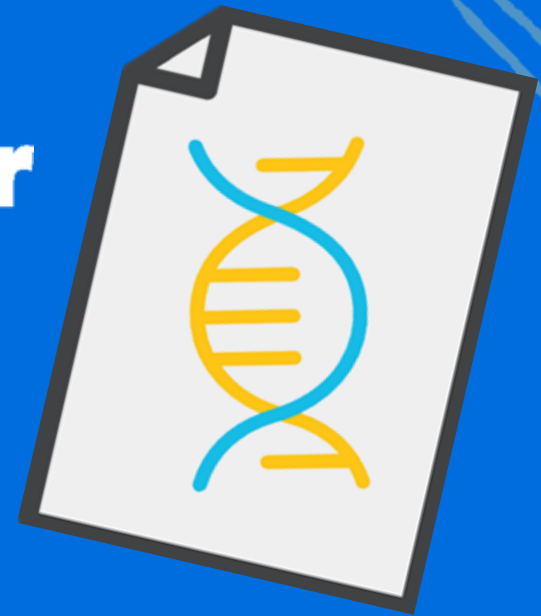
CUL3
support & awareness

QUESTIONS? Visit SimonsSearchlight.org

RESEARCH PARTICIPATION STEPS

step
2

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

Complete this Step: bit.ly/Simons_Searchlight_Dashboard

RESEARCH PARTICIPATION STEPS

step



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.

Complete this Step: bit.ly/Simons_Searchlight_Dashboard

RESEARCH PARTICIPATION STEPS

step

4

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

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—we're happy to help!**

Complete this Step: bit.ly/Simons_Searchlight_Dashboard

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