SIMONS
SEARCHLIGHT
Driven by science. United by hope.

How can we create scientific breakthroughs for rare genetic disorders?

Families and scientists must come together.

Simons Searchlight is an ambitious research program that is creating an ever-growing database and resource network. You and families like yours share valuable information and experiences that leading geneticists and scientists around the world can use to improve the lives of people living with rare genetic neurodevelopmental disorders. These researchers can also invite families to participate in their research studies in the future.

People with genetic diagnoses, their families, and scientists play equal parts in this journey. In fact, families like yours are the key to making meaningful progress.

Your unique experience could hold the clues that scientists need to find answers for you and others with rare genetic disorders.

www.SimonsSearchlight.org

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Facebook: **facebook.com/SimonsSearchlight**

Twitter: **@s_searchlight**

Youtube: **youtube.com/SimonsSearchlight**

Who can join?

We study over 150 genes that cause rare neurodevelopmental disorders, and our list is always expanding. You or your family member must have a genetic diagnosis of one of these conditions in order to join. The study is international, and families can participate in several languages. You can find our gene list and list of languages at SimonsSearchlight.org.

Why join now?

When you participate, your experiences help the medical community to understand your rare genetic disorder faster.

We track health and development over time to help answer questions about the future of people with these rare disorders.

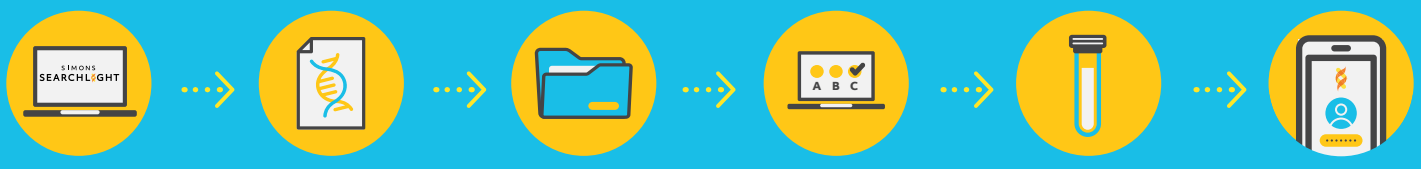
We make it easy to connect you to researchers who want to include you or your child in research studies and clinical trials.

"We are beyond grateful for what Simons Searchlight has done for our community. Most doctors have never heard of our condition and by participating, we have been able to give our doctors actionable information for care and treatment of symptoms. Simons Searchlight is more than a patient registry, they are giving families a chance to actively drive research forward." - **Jennifer, Parent**

By registering in the Simons Searchlight community, you can:

- Learn **how you or your child compare to others** in your genetic community through summary reports and presentations.
- Receive **gift cards** for completing surveys.
- **Maintain your privacy**. Your identifying information, such as your name, address, and birthday, are not shared with researchers.
- **Connect with others** who have your diagnosis through our Facebook community and by attending conferences.
- Make a difference by contributing information:
  - to help develop **care guidelines** for patients and
  - for **research** that may help you and other families.
- Be invited to **participate in new studies** of the natural history or treatment of your genetic disorder.

How to participate?



STEP 1
Sign up online.

STEP 2
Provide your genetic lab report.

STEP 3
Share your important medical history.

STEP 4
Fill out surveys.

STEP 5
Provide a blood sample if you are interested.

STEP 6
Update us every year.