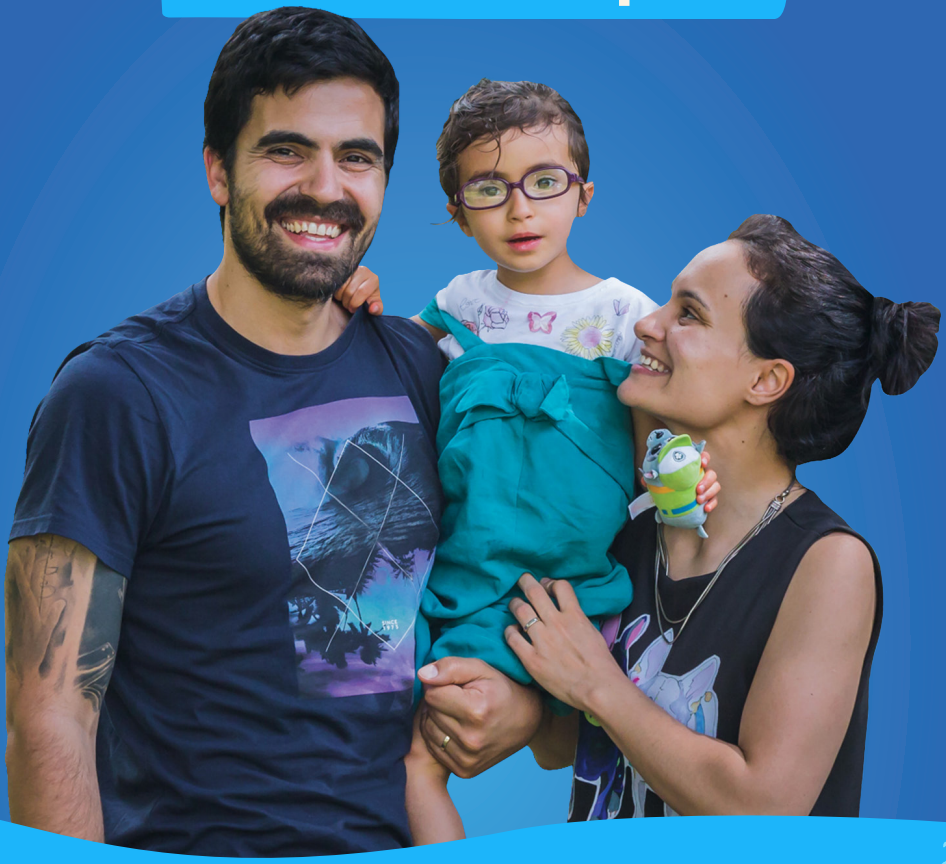
SIMONS
SEARCHLIGHT

Global Research.
Trusted Resources.
Real-World Impact.



An international research program advancing understanding of 180+ rare genetic neurodevelopmental conditions

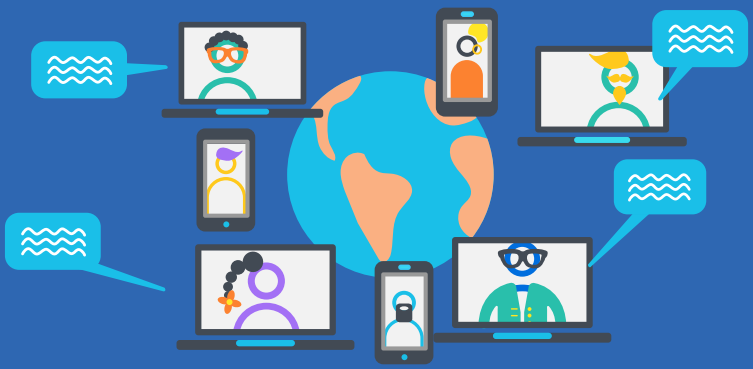
About Simons Searchlight

Simons Searchlight is an online, international research program funded by the **Simons Foundation** through the Simons Foundation Autism Research Initiative (SFARI).

We partner directly with **individuals, families, patient advocacy organizations, researchers, clinicians, and industry** to advance research, improve understanding of 180+ rare genetic conditions, and support real-world impact.

Our research cohort brings together:

- Individuals with confirmed genetic diagnoses
- Participants from 90+ countries
- Multilingual participants across seven languages (English, Dutch, French, German, Italian, Portuguese, or Spanish)



For Researchers, Clinicians, and Industry

Access Research-Ready Data & Biospecimens

Simons Searchlight collects participant-reported survey data and blood samples. Qualified researchers may request access to **de-identified phenotypic and genetic variant data, and biospecimens,** through **SFARI Base** to support research, translational science, and clinical trial readiness. Longitudinal data enable tracking health and development over time, improving our understanding of condition progression and variability.

Simons Searchlight Research Cohort Overview

- **Clinical genetic report findings:** Certified genetic counselors rigorously interpret genetic variants from lab reports and medical records shared by participants, updating variant classification as indicated by their periodic re-investigation
- **Biospecimens:** Samples including induced pluripotent stem cells (iPSCs), peripheral blood mononuclear cells (PBMCs), whole blood DNA and lymphoblastoid cell lines (LCLs)
- **Medical and developmental history:** Detailed data, including medical conditions, developmental and behavioral issues, psychiatric diagnoses, and medication use and effectiveness
- **Standardized measures:** Includes validated tools like the Vineland Adaptive Behavior Scales (Third Edition), Child Behavior Checklist, and others
- **Key domains:** In-depth data on communication, sleep, seizures, quality of life, behavior, and development
- **Longitudinal data:** Families submit baseline data and annual updates for select surveys, building a longitudinal dataset all in one place
- **De-identified and research-ready:** All data are anonymized and available for request by qualified researchers
- **Data linkage:** Option to connect Simons Searchlight data with other datasets through the Clinical Research ID (CRID), when available
- **Recruitment for external studies:** Cohort participants may be invited to participate through the Simons Searchlight Research Match Program

Request data access:
BASE.SFARI.ORG

Data & biospecimen inquiries:
SDBR@SimonsFoundation.org

SCAN FOR **GENE LIST**

Share Expert-Reviewed Resources With Patients

Simons Searchlight offers trusted, family-friendly resources developed and reviewed by **certified genetic counselors**, including:

- **Genetic Condition Guides** with plain-language summaries of current medical literature
- Education on navigating a new genetic diagnosis and understanding the difference between **clinical and genetic diagnoses**
- Connections to patient advocacy organizations, quarterly data reports, family stories, videos, and research updates

Clinicians and researchers are encouraged to refer patients and families to Simons Searchlight as a **centralized, trusted resource** for genetic education and research participation.

Learn more and **access resources** at **SimonsSearchlight.org**

Contact us

Website: SimonsSearchlight.org
Email: Coordinator@SimonsSearchlight.org

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