For PAG website promoting Simons Searchlight

Join Simons Searchlight: Empowering Families, Advancing Research on [GENE/CNV NAME]

Simons Searchlight is an online international research program funded by the Simons Foundation Autism Research Initiative (SFARI). Participation in Simons Searchlight is open worldwide to individuals with a confirmed genetic diagnosis from their list of eligible genetic conditions.

A long-standing platform for 15+ years, their primary focus is collecting natural history registry data from individuals and families with specific genetic variants associated with autism, seizures, developmental delays, ADHD, and related neurodevelopmental disorders. Currently, Simons Searchlight collects detailed family, medical, developmental, and behavioral information through online surveys.

Why Work with Simons Searchlight for Online Data and Biosample Collection?

Since 2010, Simons Searchlight has led the way in gathering crucial, long-term data on rare genetic disorders. Their online platform offers a secure space for families worldwide to share insights on genetics, development, medical history, behavior, communication, and motor skills.

How Simons Searchlight Collects Your Valuable Information

- Long-Term Surveys: Share details about your medical history and behaviors for a comprehensive view of your experiences and to better understand how your condition evolves over time.
- Optional Blood Samples: Donated blood may be used to make research resources, including cell lines, DNA samples, and induced pluripotent stem cells or iPSC. Choosing not to provide a sample won't affect other aspects of your research participation.

Read more about Simons Searchlight Data & Biosample Collection on their website and highlighted in the graphic below.

Phenotypic Information We Collect

What information is collected from individuals with genetic variants‡?		Baseline	Annual
Demographic & Genetic	Background History	X	
	Clinical Genetic Lab Results	X	
Medical & Seizures	Medical History, Medication Use	X	X
	Previous Diagnoses (Developmental, Psychiatric)	X	X
	Seizure History	X	X
Sleep	Children's Sleep Habits Questionnaire*	X	
	Simons Searchlight Sleep Supplement	X	
Developmental & Behavioral	Vineland Adaptive Behavior Scales-3*	X	X
	Observer-Reported Communication Ability (ORCA)*	X	X
	Child Behavior Checklists (1.5-5 yr, 6-18 yr)*	X	X
	Adult Behavior Checklist*	X	
	Social Responsiveness Scale-2 (School Age)*	X	X
	Social Communication Questionnaire*	X	
	Quality of Life (Qi-Disability*, PedsQL Family Impact*)	X	
	Brief Developmental Update (Communication, Mobility)	X	X

SIMONS SEARCHLIGHT

‡Includes variants of uncertain significance, likely pathogenic, and pathogenic variants
**Publisher measure*

***Simons Searchlight has an established process to collect blood from families living in the United States*

Here are additional reasons why our community partners with Simons Searchlight for research data collection:

- Expert Support: Access genetic counselors for guidance and result explanations.
- Participant Focus: Research prioritizes your needs and important questions.
- Appreciation: Receive digital gift cards as thanks.
- Global Access: Join from anywhere in multiple languages.
- Global Researchers: Simons Searchlight shares de-identified data with qualified researchers for IRB-approved projects.
- Direct Assistance: Staff are always available to answer your research questions.

Relevant resources:

- Read the full Simons Searchlight consent form to stay informed
- Watch this short video to find step-by-step instructions on how to register for Simons Searchlight, visit their website for information or review the step-by-step graphic below:

Sharing Data Insights Back With Researchers and Participants

Simons Searchlight's main goal is to speed up research and uncover information that's important to your genetic community. Your contribution is crucial for making new discoveries, but Simons Searchlight understands that these findings need to be shared to help others too. They want individuals, their families, and researchers to benefit from the knowledge gained.

For Researchers:

Researchers worldwide can request access to de-identified data through SFARI Base, which helps drive new discoveries. Over 120 scientific papers have used Simons Searchlight data.

Data, PBMCs, and iPSCs

Researchers worldwide can request access to de-identified Simons Searchlight data and biospecimens through SFARI Base. Blood samples collected through Simons Searchlight are processed into resources including DNA, PBMCs, plasma, and selected induced pluripotent stem cell (iPSC) lines.

Requesting PBMCs

Researchers can request PBMCs through SFARI Base to generate iPSCs using their own funding and expertise. iPSC lines created through this process are returned to the SFARI biorepository and made available to the broader research community.

Researchers interested in targeted blood collection for specific genetic conditions may also submit the SFARI/Simons Searchlight Gene Interest for Blood Collection Form. This helps SFARI assess scientific needs but does not guarantee blood collection or iPSC generation.

SFARI-Supported iPSC Generation

Researchers may also nominate existing PBMC samples for SFARI-funded iPSC generation through the Request for Nominations (RfN) program. Funding decisions are based on scientific merit and alignment with SFARI's mission. Researchers can continue to request PBMCs for self-funded iPSC generation at any time through SFARI Base. More information will be found on SFARI.org.

How to Request Access Data & Biospecimens

Follow these three steps:

1. Create a SFARI Base account at base.sfari.org.
2. Request the specific datasets you need, such as Simons Searchlight datasets.
3. The SFARI Data and Biospecimens Repository (SDBR) team will review and approve your request within two weeks.
4. Researchers can start today by visiting SFARI Base or emailing sdbr@simonsfoundation.org.

For Participants:

- Summarized and Personalized Research Updates: New findings are shared through conferences, webinars, quarterly reports, and personalized results about you and your genetic community on your dashboard. Personalized results available for the SCQ, SRS, CBCL and Seizure History Survey.
- Gene-Specific Community Pages: Visit your genetic community's webpage featuring current data reports, support resources, family stories and more.
- Summarizing Scientific Publications: Discover research papers enabled by families via the Simons Searchlight research registry on our 'Publications' webpage. See firsthand how participants' contributions drive translational science and empower families worldwide.

By sharing information over time, individuals contribute to new discoveries about their condition, helping to transform knowledge into benefits for their genetic community now and for future generations.

Relevant videos and links:

- The Impact of Participation and Data in Genetic Research
- Dr. Thomas Frazier's Webcam and AI Study Drives Discovery
- Simons Searchlight Values Collaborations to Advance Research
- Researchers Using Simons Searchlight Data

- Researcher Profiles: Interviews with researchers who have used Simons Searchlight data

Join Simons Searchlight

Be part of a cause that matters. Join Simons Searchlight today and contribute to empowering families and advancing research for the [GENE NAME] community. Learn more and get involved at SimonsSearchlight.org.

Questions? Reach out to the Study Coordinators with any questions at Coordinator@SimonsSearchlight.org.

For PAG newsletter and emails promoting Simons Searchlight

[PAG name] is partnering with Simons Searchlight to help advance research on [GENE - related syndrome] - join Simons Searchlight today!

Simons Searchlight is our trusted research partner focused on understanding rare genetic neurodevelopmental disorders, including autism, seizures, and developmental delays. Since 2010, they've been collecting valuable data from families like yours.

Why Participate in Simons Searchlight?

1. **Comprehensive Data & Blood Sample Collection**: Through online surveys (e.g. Annual Medical History, Vineland, Seizure History, Child Behavior Checklist, etc.) and optional blood samples, Simons Searchlight gathers crucial information on genetics, development, behavior, and more. Donated blood may be used to make research resources, including cell lines, DNA samples, and selected induced pluripotent stem cells or iPSCs. This combined data forms a powerful toolkit for researchers.
2. **Expert Support**: Participants have access to Simons Searchlight genetic counselors and study coordinators who provide support and explain results.
3. **Global Impact**: Your de-identified data helps researchers worldwide, accelerating discoveries and improving understanding of [GENE]-related conditions.

4. **Sharing Data Insights**: Simons Searchlight shares new summarized data findings with families and researchers through presentations, reports, and publications.

Visit their webpage to learn more about the importance of participating in research through online data and biosample collection.

Register for Simons Searchlight and Ask Your Questions

Join Simons Searchlight today and be a vital part of important long-term research. Your participation can help drive new discoveries and benefit current and future families.

Visit the Simons Searchlight website to learn more: https://www.simonssearchlight.org

Questions? Reach out to the Study Coordinators with any questions at Coordinator@SimonsSearchlight.org.

For PAG social media promoting Simons Searchlight

[PAG name] is partnering with Simons Searchlight to help advance research on GENE -related syndrome - Join Simons Searchlight today! 🧬

Since 2010, Simons Searchlight has been key in studying rare genetic disorders like [GENE/CONDITION]. Here's why you should join their research program and participate:

🔬 Data & Samples: Share important online survey information and optional blood samples to support vital research. Bonus: earn online gift cards for completing surveys!

👩‍⚕️ Expert Support: Access genetic counselors and study coordinators to help you with research participation.

🌍 Global Impact: Your data helps researchers worldwide make new discoveries.

📚 Gene Webpages: Find medical information, developmental history, and behavioral data in your community's gene guide. Download and share these resources with your family, healthcare provider or school!

Be part of the solution! Register at www.SimonsSearchlight.org and contact Coordinator@SimonsSearchlight.org with any questions.

#SimonsSearchlight #RareDiseaseResearch
[add graphic to post]