

Virtual Connect - February 2026 Q&A

1. Q: How can we contribute to Simons Searchlight if outside the US?

Thank you for your question. Simons Searchlight is an international research program, and families from around the world are welcome to participate. Currently, participation is available in English, Dutch, French, German, Italian, Portuguese, and Spanish, and we continue to expand translations to make surveys and resources more accessible globally.

If an individual has a [qualifying rare genetic neurodevelopmental diagnosis](#), they may enroll from any country at SimonsSearchlight.org and contribute data that supports research worldwide.

We encourage patient advocacy groups to work with local, reputable scientists to understand their research efforts that benefit your community. Researchers are able to apply for access to SFARI resources.

2. Q: Is this process for new genetic conditions, or related to known ones already in the repository? As patients, can we send samples to be analyzed?

Simons Searchlight currently studies [184 rare genetic neurodevelopmental conditions](#). The list of included conditions has evolved over time and may expand through a formal [gene nomination](#) and scientific review process led by SFARI. The decision to add a new condition is based on scientific need and reviewed by an expert committee. At this time, families cannot independently submit samples for diagnostic analysis through Simons Searchlight. Participation and sample collection are coordinated within the scope of approved study protocols for included conditions.

3. Q: How long does the process take from data request to approval and access?

If a researcher's institution already has an executed Research Distribution Agreement (RDA) in place, scientific approval and access for data is typically granted within 2–3 weeks or less.

If a new RDA must be reviewed and signed by the researcher's institution, timelines may vary depending on the institution's internal review process and signing official.

4. Q: Can a PhD scientist affiliated with a PAG request data access? Must they be affiliated with a university? Can for-profit pharma companies request data?

A PhD-level scientist affiliated with a PAG may request data access if they hold an investigator-level or equivalent position and are submitting a defined research project. An application must include a research abstract outlining the proposed study.

For-profit companies, including pharmaceutical organizations, are also eligible to apply for data access, subject to the same review and approval process.

5. Q: Can I receive a copy of the RDA for iPSCs?

iPSCs are distributed under the Research Distribution Agreement (RDA). A copy of the RDA is publicly available on the SFARI Base section of the [sfari.org](https://www.sfari.org) website.

6. Q: Is Simons Searchlight structured to contribute to pharmaceutical development? For example, HIPAA compliance and validated endpoints like Vineland?

Simons Searchlight is structured to support translational research. The study collects standardized, validated measures such as the Vineland Adaptive Behavior Scales in parallel to in-house designed surveys (visit the [Researcher Welcome Packet](#) for a complete list of assigned surveys).

Simons Searchlight implements robust privacy and data protection practices aligned with applicable research and data standards, including safeguards comparable to those required under HIPAA (U.S.) and GDPR (Europe).

Data and biospecimens are curated to support rigorous scientific research, including preclinical and clinical development efforts.

Q: Regarding Research Match: if a researcher needed to recruit controls (including family members), how long would it take? Is IRB approval required?

All Research Match studies require prior IRB approval before a researcher can submit a study application to [SFARI Base](#). Recruitment of unaffected controls, including family members when appropriate, is supported through the platform.

On average, studies take approximately 2–4 months from approval to launch, though timelines vary depending on study complexity and recruitment criteria. Online survey studies may take longer to develop than "handoff" studies that connect participants directly with research teams. The Research Match team works closely with investigators to determine eligibility criteria, recruitment strategy, and timeline.

7. Q: How can a PAG become known to Simons Searchlight? If a PAG already has its own patient cohort, is that a conflict?

We welcome engagement from PAGs and encourage outreach to our team at Coordinator@SimonsSearchlight.org to explore collaboration opportunities.

Having an independent patient cohort is not inherently a conflict. In many cases, complementary data efforts can strengthen research impact. We are happy to discuss alignment, shared goals, and ways to collaborate that benefit families and advance science.

8. Q: Can European medical researchers access Simons Searchlight data? Are the legal requirements different?

Yes. Simons Searchlight data are available to qualified researchers in Europe and globally. The application process and requirements are the same regardless of geographic location. Simons Searchlight implements robust privacy and data protection practices aligned with applicable research and data standards, including safeguards comparable to those required under HIPAA (U.S.) and GDPR (Europe).

9. Q: If a researcher wants to collect new survey data not currently in the repository, how would Research Match work?

After a researcher submits an application through [SFARI Base](#) and receives approval, there are two primary pathways:

- **Platform-based survey:** The Research Match team builds the survey within the platform, invites participants, and provides the research team with deidentified data.
- **Handoff model:** With participant permission, contact information is shared with the research team, which then conducts the study directly (e.g., surveys, interviews, clinic visits).

The most appropriate pathway depends on study design, IRB approval, and project needs. The Research Match team works collaboratively with investigators to determine the best approach. Please send any interested researchers to learn more here:

<https://www.sfari.org/resource/research-match/>