

Simons Searchlight Recruitment Process Document

Overview: Simons Searchlight

What is Simons Searchlight?

Simons Searchlight is a research registry for genetic conditions associated with autism and neurodevelopmental disorders. Funded by the [Simons Foundation Autism Research Initiative](#) (SFARI), Simons Searchlight collects parent-reported medical, developmental, and behavioral information, in addition to biospecimens, in order to share with researchers and catalyze progress towards treatments.

For more information on Simons Searchlight, please visit the [Simons Searchlight website](#) and the SFARI website for the [Simons Searchlight cohort](#). For questions about requests for resources and new recruitment studies, please visit the [SFARI Base page](#).

What resources are available for my research project?

Qualified, approved researchers can request access to phenotypic data, biospecimens, genetic data or to recruit Simons Searchlight families for additional studies (research match) via the web portal [SFARI Base](#).

Simons Searchlight will announce new releases of data via SFARI.org newsletters, SFARI.org website or Simons Searchlight twitter.

A full list of phenotypic measures given to Simons Searchlight participants is [available here](#). Since Simons Searchlight is an online study, participants choose which measures to complete and at what time. Therefore, any given participant may have different phenotypic data available.

For information on requesting data and biospecimens, please visit the [SFARI Base page](#).

This document provides additional information on recruiting Simons Searchlight families for your new research project, and you may contact collections@sfari.org with any specific questions regarding your potential project.

How do I get permission to recruit Simons Searchlight families to participate in my research project?

If you want to recruit Simons Searchlight families as research participants, you will need to follow the recruitment study process as detailed below. Please note that you will need to place a separate request and receive SFARI approval for access to phenotypic or genetic data. If you would like to access recruited participants' coded Simons Searchlight data and link to the data you collect in your new study, you will need to include authorization language (bidirectional data-sharing language) in your study's consent form(s). Please work with the

Simons Searchlight recruitment liaison to ensure you will be able to access the data.

Overview: Recruiting Simons Searchlight Participants (Research Match)

Investigators interested in conducting research studies with Simons Searchlight families can initiate a new recruitment study request through [SFARI Base](#). See [here](#) for additional details about submitting a new recruitment study request.

As an investigator, you will be required to create a log-in name and password, affiliate with an institution, sign the joinder agreement to the Researcher Distribution Agreement (RDA) and complete a new recruitment study request application. For new recruitment studies involving Simons Searchlight participants, we have a rolling application process.

After you have submitted your application:

1. A SFARI support team member will contact you to confirm the details of your request, including the eligibility criteria and number of participants. If needed, the support team member will also put you in touch with the Simons Searchlight recruitment liaison to begin planning your study materials.
2. Your request will be reviewed by the appropriate committee. You will be notified when your request is approved. A SFARI support team member will notify you if additional details are required or if your request needs to be revised and resubmitted. Sometimes requests are not approved. If this happens, someone from SFARI will contact you with an explanation. **Note:** If you have questions about the review and approval process, please contact collections@sfari.org.
3. Upon approval of your request, your project's information will be sent to the Simons Searchlight recruitment liaison. You will be contacted to schedule an introductory call with the Research Match team. You may also need to provide other documentation (e.g., recruitment materials). **Please note, it is not mandatory to draft recruitment materials prior to the call. If you decide to draft recruitment materials prior to the call, it is strongly encouraged that you send your recruitment materials to the Simons Searchlight recruitment liaison for review before submitting them to your IRB.**
4. In order to launch your new recruitment project, you will work directly with the Simons Searchlight recruitment liaison, Research Match team and our information technology team (Tempus Dynamics) regarding the timeline and other recruitment project details. Specific study workflows vary depending on the study protocol (see below for details on types of studies). Please note that authorization to contact Simons Searchlight participants is limited to only the approved study and, as such, Simons Searchlight participants may not be asked to consent to join a lab's local

research registry or to agree to be contacted about future research not approved by Simons Searchlight.

5. Projects are approved to recruit for one year. Recruiting participants from Simons Searchlight past one year requires a renewal application and is contingent on approval from the Simons Searchlight PAC. The renewal application requires researchers to provide a summary of recruitment efforts over the past year and scientific justification for continued recruitment from the Simons Searchlight cohort. Projects may submit up to two renewals for consideration.

Overview: Types of Research Match Studies

All Research Match studies begin with an invitation email (see Appendix B), which tells eligible participants about your research study and encourages them to take the next step to learn more. From here, interested participants are directed down a workflow that may vary based on your specific study type and protocol. Please see some examples below.

In-clinic/hand-off studies

If you need to invite participants to visit your clinic or conduct an in-person research protocol, your study will typically use the following workflow. This workflow is also used for hand-off studies, including online tasks Simons Searchlight is unable to build, focus groups, and phone interviews. We typically determine whether your study should be a hand-off study or an online survey study during the introductory call.

Workflow:

1. After responding to the interest email, participants are directed to an online screen (Appendix A), where they can read more about your study and answer additional eligibility questions (if applicable).
2. If interested and eligible, participants electronically sign an authorization form (Appendix A) granting permission for Simons Searchlight to send their contact information to your lab. You will be able to access the information on participants who granted this authorization through a secure web portal. In addition to the contact information, a Temporary Recruitment ID will be provided for each participant.
3. Contact families to obtain their consent to participate in your study. Follow your institutional review board (IRB)-approved study protocol for consent and other study procedures.
4. In the same secure online portal through which you obtained the contact

information, enter the consent and participation status for each participant (e.g., declined consent, consented, lost to follow-up/never responded) and other information (e.g., dates and methods of contact). The Simons Searchlight recruitment liaison will work with you to define which fields need entry for your particular study.

5. The secure online portal will make available to you the Simons Searchlight Publishable ID (SFARI Base ID) *only for participants who consented into your study*. The SFARI Base ID will allow you to identify the family in the SFARI Base data set and link to the participant's phenotypic and genetic data.

Online survey studies

If your study consists of an online survey, Simons Searchlight typically recommends allowing us to build the survey into our own workflow system. This streamlines the participant experience, increases response rates, and facilitates data sharing. The Simons Searchlight recruitment liaison can discuss your specific study details with you, and our Research Match team will work closely with you to build and test your survey, including conversion to an online format and database variable names. For online studies that include components other than a survey (e.g., custom tasks requiring additional programming, animation, or unique interactive tasks), Simons Searchlight recommends using the hand-off workflow described above.

Workflow:

1. After responding to the interest email, participants are directed straight to your study consent form.
2. If they consent, they proceed straight to your first survey and continue until they have completed the entire protocol.
3. The Research Match online system may be able to distribute electronic incentives when the participant submits the last survey in the workflow. Discuss this with the Simons Searchlight recruitment liaison to see if this is a good fit for your study.
4. At the conclusion of the study, you will receive a final data set with your study data, indexed by SFARI Base ID, so that you can link to the coded Simons Searchlight data on SFARI Base.

Frequently Asked Questions

1. How do I submit a request to recruit Simons Searchlight families as participants in my research project?

Create your request and submit your project documentation for access to Simons Searchlight resources on [SFARI Base](#).

See [here](#) for additional details about submitting a new recruitment study request. If you have any problems submitting the application or if you have additional questions about a specific field in the application, please contact collections@sfari.org.

2. How long will it take to approve my new recruitment study request?

The request will be considered by SFARI, and we will communicate with you regarding its status (approve, deny or additional questions). If you want to check on the status of your application, please contact collections@sfari.org.

3. What should I do if I need to edit my request?

Go back to your request on SFARI Base and click “Edit.” If you have difficulties, you may contact collections@sfari.org. Please also contact collections@sfari.org if your approved research protocol has changed significantly from what you originally submitted (e.g., addition or removal of a task, change in type of incentive or feedback).

4. How long does it usually take to launch a new recruitment project after approval?

Time to launch varies widely and depends on some project-specific details such as the complexity of your protocol, your IRB approval timeline, and other factors such as the need to stagger project launches to ensure optimal recruitment for all principal investigators (PIs). Typical time from the post-approval introductory call to launch is between two to four months, but actual timeline may be shorter or longer.

5. When can I expect to receive the families’ contact information (for in-clinic or hand-off studies)?

The contact information will become available to you in real time as participants authorize, following the launch of your new recruitment project. You will be able to pull this information from the secure portal as often as you wish while your study is active. Once your project closes, you will no longer have access to this information, but if needed you may retain it securely in your own files for your records (provided your local IRB protocol and consent allows for storage).

6. What options do I have for new recruitment study workflows?

You should discuss the specifics of your project with the Simons Searchlight recruitment liaison, but Simons Searchlight has the ability to

support many different kinds of research. Briefly, your options could include:

- a) Simons Searchlight can contact participants and ask them to complete an authorization to share their contact information with you. Then your lab staff can contact the participants to discuss the study and get their consent directly. This is often the option preferred by in-clinic projects.
- b) Simons Searchlight may be able to host both the authorization and your study consent form online and share with you the information for participants who provide consent.
- c) Simons Searchlight may be able to host the authorization, your consent form and online questionnaire(s). Some questionnaires may already be available, while others may be difficult or impossible for us to build online. Speak with the Simons Searchlight recruitment liaison for details.

7. Who should I contact if I have additional questions?

For all additional questions, please contact collections@sfari.org. This includes any issues with website navigation, difficulties uploading forms, questions about the fields in the new recruitment study application, and questions about the status of your application.

8. How do I find the Simons Searchlight phenotype and/or genetic data for the families that agree to participate in my study?

A Simons Searchlight participant must consent for you to link their Simons Searchlight data and new recruitment project data before we can provide you with this information. *If you wish to link data from your project and the Simons Searchlight study, you must include the bidirectional data-sharing language (see highlighted example below, under item #10) in your consent form in order to receive the identified data. This language must be approved by both the Simons Searchlight recruitment liaison and your institutional IRB.* Failure to follow this step in its entirety may result in you being unable to obtain the Simons Searchlight data.

The secure portal provided as part of your new recruitment project (the same one where you obtain the participant contact information) will track consent status (if your consent form is hosted by Simons Searchlight) or allow you to enter consent status for each participant. Once you indicate that a family has consented to participate in your study, and therefore agreed to the bidirectional data-sharing language, we will be able to show you the SFARI Base ID linked to the temporary Recruitment ID. You will be able to use the SFARI Base IDs to obtain the Simons Searchlight data on SFARI Base. The Simons Searchlight recruitment liaison can explain this process in more detail.

9. How do I know what information should be included in my new recruitment project email and authorization form? What about my consent forms?

Template email and authorization form scripts are provided at the end of this document for your convenience (Appendices A and B). You will work with the Simons Searchlight recruitment liaison to optimize these materials after your project is approved.

For your consent form, you must be sure to include two aspects of data transfer (bidirectional data-sharing language):

- a)** Consent for you (Researcher) to receive *linked, identified* phenotype and/or genetic data from the Simons Searchlight database using the participant's SFARI Base ID.
- b)** Consent to transfer participants' data from your study into the Simons Searchlight database.

You must receive approval from the Simons Searchlight recruitment liaison before submitting these consent changes to your IRB. Failure to follow this step may result in you being unable to obtain the linked Simons Searchlight data. Note that in most cases, a PI must submit one additional IRB amendment as part of the pre-project launch process. This submission should include your final, approved consent forms, authorization form with bidirectional data sharing language, and recruitment emails (invitation and reminder emails), as well as any other documents required to build your workflow as discussed with your Simons Searchlight recruitment liaison.

10. What is the bidirectional data sharing language that must be included in my consent form?

This language allows you to receive *linked, identified* data from Simons Searchlight on the participants in your study. This data is shared using a linked ID number (SFARI Base ID) that is not provided until participants consent to be in your study and sign their agreement to bidirectional sharing of their data. This language also provides consent for you to share your study's data back with Simons Searchlight, for inclusion in the Simons Searchlight database, in order to continue to enhance this resource. Suggested language is provided below. *Please allow your Simons Searchlight recruitment liaison to review your consent form(s) during the pre-project launch phase prior to resubmission to your IRB. Failure to do so, or to include the language in your consent form at all, may result in delays to and/or cancellation of your project or make it impossible for Simons Searchlight to share identified data with you.*

“(If study contains non- Simons Searchlight participants, start with: For those individuals who participated in the Simons Searchlight study,) we are asking your consent for the Simons Searchlight study, hosted by the

Simons Foundation, to share with {University} the clinical, demographic and genetic data collected during your participation in Simons Searchlight. This information will be shared using your linked research ID number and using a secure transfer system. We are also asking for your consent to share the data we collect during the study here at {University} with Simons Searchlight in order to add to the information that was collected during your participation in Simons Searchlight. Please note that because you are a participant in both studies, Simons Searchlight and this study will be able to share and link your identifying information as well as any future data you may contribute to either project.

The Simons Foundation funds innovative research and provides coded data access (data with your identifying information removed) to qualified researchers. Researchers can file an application with the Simons Foundation to obtain access to your study data for research purposes. Experts at the Simons Foundation who protect health and science information will look at every request carefully to minimize risks to your privacy.”

Please ensure that you have accounted for all “roles” (e.g., parents, siblings, individuals with a genetic diagnosis) for which you want to obtain data. Data-sharing consent must be obtained for each individual, and all independent adults must consent for themselves.

11. What is the process for data sharing with Simons Searchlight?

Once a participant has completed your study consent form (agreed to bidirectional data sharing) and you have the SFARI Base ID for a participant, you will be able to link to the data in the Simons Searchlight database.

You will also be required to share data from your study back with Simons Searchlight, to enhance the Simons Searchlight database. This will include participation data as well as study-specific data. Simons Searchlight will work with you on the terms of this data sharing, but in general, the expectation is that data will be made available for Simons Searchlight to distribute to researchers publicly upon publication or within one year of the end of data collection, whichever comes first. These terms are also outlined in the [Researcher Distribution Agreement](#), which your institution signed, and the Joinder to the RDA that you acknowledged when you first created an account on SFARI Base.

We will also ask for your help creating a lay-friendly summary of your research to share with Simons Searchlight participants when recruitment for your project is completed.

12. Is there a fee for Simons Searchlight recruitment services?

At this time, Simons Searchlight does not charge a fee. However, this policy may change in the future, in which case documentation will be provided/updated. Research teams are responsible for any licensing and copyright fees for use of standardized measures in their studies. Any requests for custom tasks may incur additional charge. Please contact collections@sfari.org to determine your specific study requirements and potential costs.

Checklist for New Recruitment Projects

For initial application review:

Application items in SFARI Base:

- ☐ Completed application
- ☐ IRB project approval
- ☐ IRB approved consent form
- ☐ IRB approved surveys, interview questions, and/or related project materials

Please email collections@sfari.org if you have questions related to the SFARI application and approval process.

For approved projects

The following items should be forwarded to the Simons Searchlight recruitment liaison after project approval:

- ☐ Any updated IRB materials (including final surveys), or templates from Appendix A and B, if not already sent in the application.

After your final study materials are approved and submitted to your institutional IRB:

- ☐ Final IRB project approval
- ☐ Final IRB-approved consent form
- ☐ Final IRB-approved authorizations, scripts, and emails
- ☐ (If applicable) Final IRB-approved survey(s)

Typically, communication regarding recruitment materials begins after SFARI approval. However, in certain circumstances, it may be necessary to initiate communication earlier. Please discuss with the Simons Searchlight recruitment liaison via collections@sfari.org.

Please be aware:

- As a result of a successful authorization, you will receive only a limited amount of information on participants, via the secure portal hosted. This includes names, contact information and a Temporary ID. You must contact and get consent from participants in order to receive additional information and the SFARI Base ID.
- Data transferred as a result of an authorization CANNOT be used for

research unless/until the individual(s) in question have consented for a project. The data transferred during authorization expire and must be destroyed by the researcher after one year if the research participant does not join the study.

- Data transferred as a result of an authorization CANNOT be used for any study other than the approved study. Simons Searchlight participants may not give consent to be contacted by your lab about additional research opportunities unless this has also been approved by the Simons Searchlight review committee.
- For every individual, including other family members, for whom you want Simons Searchlight data, you must have consent, authorization or some other IRB-approved process in place. Make sure to have a strategy to obtain all identified Simons Searchlight data that you need for your analysis. Discuss with the Simons Searchlight recruitment liaison if you have questions about this process.

Appendix A – Authorization Template

Recruitment Project Authorization Online Screens for Simons Searchlight

In this template, items that will always appear no matter what study is recruiting appear in black. Researchers provide text for the green items to fit their study's criteria.

Additional Study Information [Screen 1]

Here, the outside study is explained in more detail. This may include the goals of the study, eligibility criteria, what participation involves, how much time it will take to participate, and any incentives provided. The explanation must contain language reassuring the participant that they do not have to answer any specific questions and can withdraw from the study at any time. It must also include the following: Participating (or choosing not to participate) in this study will not change your participation in the Simons Searchlight study. You may also choose to withdraw your participation at any time.

Eligibility Question(s):

For most studies, families will be eligible based on their Simons Searchlight status or information we already possess and have screened for (such as child age). If there are any additional eligibility criteria, we will screen for them here.

Please keep questions simple (e.g., yes/no answers) and list the pass/fail criteria.

Participation/Authorization Section:

Please note that Simons Searchlight is serving as a resource linking Simons Searchlight families and researchers who are conducting research families may wish to join. This study is not part of the main Simons Searchlight study. You do not have to participate in this new study. Not participating will not affect the care you receive from any health provider nor your standing as a participant in Simons Searchlight. Please note: This study is being performed by [NAME OF INSTITUTION]. Simons Searchlight is not conducting nor endorsing this research project.

[IF STUDY INCLUDED ELIGIBILITY CRITERIA, THIS SECTION WILL APPEAR AS A SEPARATE PAGE; COPY STUDY DESCRIPTION FROM PAGE 1 HERE]

1. [FULL NAME], would you be interested in participating in the [STUDY TITLE] study?

- Yes
- No

2. [Shows only if answer to #1 is YES] We request that you grant Simons Searchlight and the **[NAME OF INSTITUTION]** research team permission to share information as described below.

Read the authorization, and then click “yes” or “no”, as you choose.

I HEREBY AUTHORIZE

1) The **[NAME OF INSTITUTION]** research team to release information about my involvement in the **[STUDY TITLE]** study to Simons Searchlight so the Simons Searchlight team will know how many families were interested in, started, and actually completed the study.

and

2) Simons Searchlight to release the information listed below for [designated family members such as Parent(s), Child(ren) with genetic condition, Sibling(s) without genetic condition] to the **[NAME OF INSTITUTION]** research team so they can **contact me** about study participation and **link information** they collect through the study with information already collected through my family’s participation in Simons Searchlight. (This makes research more efficient because the team won’t need to ask you to do the same tests, interviews, or surveys again. They can spend their time with you and your family addressing new research questions but still access relevant information from these earlier studies to help them in their analysis.)

- Last Name, First Name, and Middle Initial
- Simons Searchlight ID Number
- Mailing Address
- Email address and preference regarding which address researchers should email
- Phone numbers and preference regarding which number researchers should call
- Gender
- Date of birth
- Genetic diagnoses
- **Additional information depending on study protocol**

This authorization will expire one year from today’s date. I understand that I may revoke this authorization in writing (submitted to the Simons Searchlight team) except to the extent that action has already been taken. I understand that this authorization is voluntary. I understand that my and my family’s participation in Simons Searchlight will not be affected if I do not grant

authorization for sharing of information and if I do not join this particular study.

On behalf of [myself, my child(ren) with the genetic condition, their sibling(s) without the genetic condition, etc.], I grant authorization for the exchange of information described above:

- Yes
- No

Please note: checking yes above is the equivalent of providing your signature on this authorization form. You may print out or save a copy of this form for your records.

Appendix B – Email Templates

Recruitment Project Email Templates (page 15 & 16)

In these templates, items that will always appear no matter what study is recruiting appear in black. Researchers provide text for the green items to fit their study's criteria. Please consider using participant-friendly language and avoid complex, lengthy explanations in your invitation email.

To edit the emails, double click the template and it will open in a new Microsoft Word document.

Invitation email template for Simons Searchlight Recruitment Studies

Subject: [Customized to fit project]. Examples include: “Invitation: Research Study about [study topic]” or “New research opportunity from Simons Searchlight” or “New study recruiting Simons Searchlight participants” ending with (SLO###PI Last Name)



Research Match

New Research Study Opportunity

Study Name: Customized to fit the project

Dear NAME,

You are invited to participate in a new research study at [INSTITUTION NAME] led by [RESEARCHERS NAMES].

Study Information



What is involved?

- Brief, plain language description of what the participant will be asked to do. (1-3 sentences)



Purpose of the research

- Briefly describe what your research is trying to find. (1-2 sentences)



You may be eligible if

- Your child/you are ages [age range]
- Any other important inclusion criteria here



What will I receive if I participate?

- Is there an incentive for participation?
- Are transportation and parking costs covered? (if there are in-person visits)
- Do participants receive a report/evaluation?

To learn more, click the link below:

LEARN MORE

If you are NOT interested in this study, let us know and we will not send you any additional emails about the study. Not interested? Click [here](#).

This section thanks the family for their time, attention, etc. (1 sentence)

Sincerely,

Researcher’s Name
Institution

Why am I receiving this email?

When you joined Simons Searchlight, we promised to contact you about new research projects. This is an invitation from a research team looking for Searchlight families to participate in their study. Contact Searchlight at researchmatch@simonssearchlight.org if you have any questions about this research invitation.



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researchmatch@simonssearchlight.org

Simons Searchlight Simons Foundation PO Box 1806 New York, NY 10159

Reminder email template for Simons Searchlight Recruitment Studies

Subject: [Customized to fit project. Examples include: “Reminder: Research Study about [study topic]” or “Reminder: New research opportunity from Simons Searchlight” or “Reminder: New study recruiting Simons Searchlight participants” ending with (SL0###PI Last Name)]

SIMONS
SEARCHLIGHT

Research Match

Research Study Opportunity Still Available

Study Name: Customized to fit the project

Dear NAME,

You are invited to participate in a new research study at [INSTITUTION NAME] led by [RESEARCHERS NAMES].

Study Information



What is involved?

- Brief, plain language description of what the participant will be asked to do. (1-3 sentences)



Purpose of the research

- Briefly describe what your research is trying to find. (1-2 sentences)



You may be eligible if

- Your child/you are ages [age range]
- Any other important inclusion criteria here



What will I receive if I participate?

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This section thanks the family for their time, attention, etc. (1 sentence)

Sincerely,

Researcher’s Name
Institution

Why am I receiving this email?

When you joined Simons Searchlight, we promised to contact you about new research projects. This is an invitation from a research team looking for Searchlight families to participate in their study. Contact Searchlight at researchmatch@simonssearchlight.org if you have any questions about this research invitation.



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