

Simons Simplex Collection: Research Match Recruitment Process

Overview: Simons Simplex Collection

What is the Simons Simplex Collection?

The Simons Simplex Collection (SSC) is a resource of phenotypic and genetic data and biospecimens for use by autism researchers. The SSC is the result of a collaboration between the Simons Foundation Autism Research Initiative (SFARI) and [12 university-affiliated research sites](#) across North America to establish a permanent repository of genetic samples and phenotypic data from more than 2,700 families.

Each family in the SSC has one known child affected with an autism spectrum disorder, and unaffected biological parents and siblings. Rigorous phenotyping helped ensure consistency in assessment and diagnosis across the 12 sites. For more information on the SSC, please visit the [SSC cohort](#) webpage on SFARI.org and download the researcher welcome packet.

What resources are available for my research project?

Qualified approved researchers can request access to biospecimens, phenotypic data, and genetic data, or ask for contact information to recruit SSC families for additional studies via the web portal [SFARI Base](#). As of early 2025, all probands in the study are at least 18 years of age. Families were sent a guardianship status form at the time of 'aging-up' to indicate if the proband is a dependent or independent adult, including the option to remain in the registry.

Approximately 6,000 phenotype variables were collected from each family, including an extensive medical history and data from numerous published instruments. Nearly all families provided whole blood for each participant. Information about the DNA extracted from whole blood (WB-DNA) and from immortalized lymphoblast cells (LCL-DNA) is available by request, as are the lymphoblastoid cell lines (LCLs) and plasma from all mothers and probands (affected individuals). For information on requesting data and biospecimens, please visit the [SFARI Base resource page](#).

This document provides further information on recruiting SSC families for your new research project. For any specific questions regarding your potential project not addressed in this document, please contact the SFARI Data and Biospecimen Repository (SDBR) team at SDBR@simonsfoundation.org.

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

If you want to recruit families as research participants, you will need to follow the Research Match process detailed below. Please note that you will need to place a

separate request and receive SFARI approval for access to phenotypic and/or genetic data and to receive biospecimens.

If you would like to access recruited participants' de-identified SSC data and then 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 SSC recruitment liaison to ensure you will be able to access the data.

Overview: Recruiting Simons Simplex Collection Participants (Research Match)

Research Match is a service that enables approved researchers to recontact participants from SFARI autism cohorts, including SSC, for recruitment into new research studies.

Investigators interested in conducting research studies with SSC families can initiate a Research Match request through [SFARI Base](#). The process for placing a Research Match request is detailed on the [SFARI.org resources page](#).

Briefly, you will be required to create a login name and password, affiliate with an institution, sign the joinder agreement to the Researcher Distribution Agreement (RDA), and complete a Research Match request application.

After you have submitted your application:

1. A SFARI support-team member will contact you to confirm the details of your request, including the selection criteria and number of participants. If needed, the support-team member will also put you in touch with the SSC recruitment liaison to begin planning your study materials.
2. Your request will be reviewed by the appropriate committee. You will be notified if and when your request is approved. If additional details are required, or if your request needs to be revised and resubmitted, a SFARI support-team member will notify you. Not all requests are approved. If yours is not, someone from SFARI will contact you to explain why your request was denied. **Note:** For any questions about the review and approval process, please contact SDBR@simonsfoundation.org.
3. If your request is approved, your project's information will be sent to the SDBR team. You will need to work directly with the SSC Registry team regarding the timeline and other recruitment project details. After the SSC Registry team contacts each family to obtain permission to send their contact information to your lab, the SSC Registry team will send you contact information for those families that have granted permission to be approached. A five-digit ID will be provided for each family along with their contact information. **Note:** If you have questions at any time for the SSC Registry team, please contact SDBR@simonsfoundation.org.

4. On contacting the families that have allowed access to their addresses, your study team will need to request consent to participate in your study, and compile a list of the families that have agreed to participate in your study.
5. Your study team will then need to send the list of five-digit family IDs for those families that consent to participate in your study to SDBR@simonsfoundation.org.
6. An SDBR team member will send you a document that links the four-digit family ID provided by the SSC Registry to the SFARI ID used to identify the family in the SFARI Base dataset. **Note:** Some studies may be able to utilize an admin portal to access the SFARI ID. The SDBR team will discuss the specific details with you after your project is approved.

Frequently asked questions

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

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

For additional details about submitting a new-recruitment-study request, see [the SFARI Base resources page](#). If you have any problems submitting the application, or if you have additional questions about a specific field in the application, please contact SDBR@simonsfoundation.org.

2. What documents or information must I submit with my new-recruitment (research-match) request?

Please see the description of the SSC research-match application fields below.

3. What is the SSC Registry?

The SSC Registry is a permanent online research home for those families that originally participated in the SSC Registry. Approximately 1,500 of the 2,700 original SSC families enrolled in the SSC Registry, and many are still available for recruitment into new studies. The SSC Registry team works with new investigators and SSC families to inform families about new studies, get their permission to send contact information to new primary investigators, and update them regarding research progress.

4. When can I expect to receive the families' contact information?

The contact information for families that grant permission will be accessible starting immediately after launch. The portal through which you will receive this information is updated in real time.

5. What do I do after I submit a research-match request?

Contact SDBR@simonsfoundation.org to double-check your application. The request will be considered by the SFARI science team, and we will communicate with you regarding its status (approval, denial, or additional questions).

As soon as your request is approved, you will work with the SDBR team to create the email and online authorization templates for your study (those templates can be found at the end of this document) and submit these to your IRB. Additionally, the eligibility criteria and/or list of requested families will be sent to the SSC Registry team.

The process, from submission of an application to the beginning of a new-recruitment study via the SSC Registry, typically takes from one to four months. The SDBR team will contact each family to obtain permission to send their contact information to your laboratory. The SDBR team will then send you contact information for those families that grant permission to be contacted by your lab.

6. 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 any difficulties with this process, contact SDBR@simonsfoundation.org. Please also contact SDBR@simonsfoundation.org if your protocol changes significantly from the approved protocol you originally submitted (e.g., the addition or removal of a task, or a change in the type of incentives or feedback).

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

For additional questions about issues with website navigation or difficulties uploading forms, any questions about the fields in the research-match application, or questions for the SDBR team, please contact SDBR@simonsfoundation.org.

8. How do I find the SSC phenotype data for the families that agree to participate in my study?

A SDBR team member will send you a document that links the five-digit family ID to the five-digit SFARI ID used to identify the family in the SSC dataset. (Some studies may be able to use the admin portal for this purpose.) You must include the bidirectional data-sharing language in your consent form in order to receive the identified data.

9. How do I know what information I should include in the invitation email I provide to the SSC Registry? And what details do I need to include on my consent form(s)?

Template email scripts are provided at the end of this document for your convenience. For your consent form(s), you must be sure to include two aspects of data transfer (bidirectional data-sharing language): consent for you (Researcher) to receive linked identified phenotype and/or genetic data from the SSC database using the participant’s ID, and consent to transfer participants’ data from your study into the SSC database. **Note:** *Data sharing is required for*

access to the SSC Registry. Please contact SDBR@simonsfoundation.org if you have questions about your consent language, or if you intend to make any changes to the suggested language below.

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 SFARI Base on the participants in your study. This data is shared using a linked ID number that is not provided until participants sign your study's consent form(s) indicating their agreement to bidirectional sharing of their data. This language also provides consent for you to share your study's data with SFARI Base, for inclusion in the SSC database, in order to continue to enhance this resource.

Note: *Data sharing is required for access to the SSC Registry.*

Approved language is provided in quotes below. *Please contact SDBR@simonsfoundation.org if you intend to make any changes to that language. Failure to do so, or to include the required language in your consent form at all, may result in delays to and/or cancellation of your project, or may make it impossible for the SSC to share identified data with you.*

If your study contains non-SSC participants, start with:

**"[For those individuals who participated in the Simons Simplex Collection, we"
(and continue with language below after "We").]**

If your study contains only SSC participants, use this language:

"We are asking your consent for the Simons Foundation and the SSC Registry to share with [University] the clinical, demographic, and genetic data collected during your participation in the SSC. This information will be shared using your linked research ID number and using a secure file-transfer system. We are also asking for your consent to share the data we collect during this study here at [University] with the Simons Foundation and the SSC Registry, which will be added to the information collected during your participation in the SSC. Please note that because you are a participant in both studies, the SSC 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 ASD) for which you want to obtain data. A data-sharing consent must be obtained for each individual, and all independent adults must consent for themselves.

11. Is there a fee for SSC Registry's recruitment services?

At this time, SFARI does not charge a fee. However, this policy may change in the future, in which case documentation will be provided. 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 reach out to sdbr@simonsfoundation.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
- ☐ Signed Researcher Distribution Agreement (RDA)
- ☐ IRB project approval
- ☐ IRB approved consent form
- ☐ IRB approved authorizations, scripts, and emails (**please use the templates below**).

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

For SSC Registry

The following items should be forwarded to the SSC Registry by SFARI after project approval:

- ☐ SFARI-approved application
- ☐ Final IRB project approval
- ☐ Final IRB-approved consent form
- ☐ Final IRB-approved authorizations, scripts, and emails.

The following items are sent directly to the SSC Registry by the researcher:

- ☐ IRB-approved SSC Registry authorization online form (**please use the template below**).

Typically, communication with the SSC Registry begins after SFARI approval. However, in certain circumstances, it may be necessary to initiate communication earlier. Please discuss with SDBR via SDBR@simonsfoundation.org.

Please be aware:

- As a result of a successful authorization to share contact information, SSC will release only a limited amount of information via the secure portal hosted. This includes contact information, the SSC ID, and salient medical data required for recruitment.
- Data transferred as a result of an authorization **cannot** be used for research unless/until the individual(s) in question has given consent for a project. If the

- research participant does not join the study, the data transferred during authorization expires and must be destroyed by the researcher after one year.
- For every individual from whom you want SFARI Base data, including other family members, you must have consent, authorization, or some other IRB-approved process in place. Make sure to have a strategy to obtain all central repository data that you will need for your analysis. **Data sharing is a requirement of access to the SSC Registry.** Discuss with the SSC recruitment liaison if you have questions about this process.

Email Template for SSC Registry Recontacting

In this template, sections that will appear for all research-match studies are written in black. Please provide text for the green items to fit your study's criteria.

Invitation Email with Link

Subject: New Research Opportunity for SSC participants (you may also incorporate limited information about your study topic, for example: "New research on sleep and autism for SSC families." Reminders may be sent, changing the subject line to "Still Available: [original subject line]" or "Final Opportunity: [original subject line].")



New Research Study Opportunity

When you joined the Simons Simplex Collection (SSC) Registry, we promised to inform you about SSC-focused research projects. Below is an invitation from a team of researchers seeking SSC families to participate in a new study. Email the SSC Registry team at info@simonssimplex.org if you have any questions about this research invitation.

Dear [Participant's First Name],

Briefly describe the research opportunity, what it involves, time commitment, and if there is any monetary or other incentive provided.

To learn more, click on the link below:

[Click here if interested in this study](#)

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.

In this section thank the family for their attention, etc.

Sincerely,

[Researchers' Name]
[Institution]

Research-Match Authorization Online Screens for SSC Registry

[Screen #1] Additional Study Information

Use this area here to explain the outside study in more detail. You may include the goals of the study, eligibility criteria, what participation involves, how much time it will take to participate, and any incentives provided. (See the EXAMPLE document that follows this template.) The explanation must contain language reassuring the participant that they are not required to answer any specific question they would prefer not to answer, and that they can withdraw from the study at any time.

Eligibility Questions:

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

Participation/Authorization Section:

*Please note that the SSC Registry is serving as a resource linking SSC families and researchers. You do not have to participate in this study. Not participating will not affect the care you receive from any health provider, nor your standing as a participant in the [name of original study] or the SSC Registry. **Please note:** This study is being performed by [Name of Outside Institution]. It is not endorsed by or performed under the auspices of the Simons Foundation.*

1. [Full Name], would you be interested in participating in the [**Study Title**] study?
 - Yes
 - No

2. [Included only if answer to the previous question is YES.]
We request that you grant the SSC Registry and the [Outside 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 [Outside Institution] research team to release information about my involvement in the [**Study Title**] study to SSC Registry so the SSC Registry will know how many families were interested in, started, and actually completed the study.

and

2) the SSC Registry to release the information listed below for [designated

family members such as Parent, Proband, Sib1] to the [Outside 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 the SSC. (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 while accessing relevant information from these earlier studies to help them in their analysis.)

- Last Name, First Name, and Middle Initial
- SSC ID number
- Mailing address
- Email address
- Phone numbers (home, work, or cell) and preference regarding which number researchers should call
- Gender
- Date of birth
- ASD diagnosis, or lack thereof
- Additional info 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 SSC Registry 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 the [original study name] and the SSC Registry 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 [Self, Proband, Sib1, etc.], I grant authorization for the exchange of information described above:

- Yes
- No

Click SUBMIT to finish. You will be taken to a brief "update your contact information" screen.

SUBMIT

Screen #2 (redirects to separate “contact info update” survey)

[Applicable if participant said YES to Screen #1,]

Note: This page may also be used as a stand-alone “annual contact information update survey” given to all members of the SSC Registry, to make sure that we update their contact information annually.

Thank you so much for your time and membership in the SSC Registry.

Update Your Contact Information

Please review the contact information we have on file, and update any items that have changed. The Simons Foundation and the SSC Registry prefer to stay in touch with families, including after they have moved or changed their email addresses.

1. **If an item is incorrect**, please provide updated information in the text box provided.

Name

Email

Address

Home phone

Work phone

Cell phone

2. If your address has changed, please tell us the month and year you moved to this new address. (Knowing when families lived at a certain location may help researchers studying health-care access, environmental factors, etc.)

Mo_____ Year_____

Please click “SUBMIT” below when you are finished.

Thank you for your participation in the SSC Registry. If you have any questions or need assistance, please contact us at info@simonssimplex.org.

SUBMIT