Overview: SPARK

What is SPARK?
SPARK (Simons Foundation Powering Autism Research for Knowledge) is a landmark autism research project with the mission of speeding up research and advancing our understanding of autism to help improve lives. Funded by the Simons Foundation Autism Research Initiative (SFARI), SPARK’s goal is to recruit 50,000 individuals in North America with a professional diagnosis of autism, and their family members, into an online research cohort. SPARK is the result of a collaboration between SFARI and more than 20 university-affiliated clinics and community partners. For more information on SPARK, please visit the SPARK website and the SFARI website for the SPARK cohort. For questions about requests for resources and new recruitment studies, please visit the SFARI Base Resources page.

What resources are available for my research project?
Qualified, approved researchers can request access to phenotypic data, genetic data, or to recruit SPARK families for additional studies via the web portal SFARI Base. Biospecimens may be available in the future.

Please note that phenotype and genetic data for an individual participant may not be released at exactly the same time. SPARK will announce new releases of data via SFARI.org newsletters and SPARK Research newsletters. For a full list of measures available for SPARK participants, please refer to the Researcher Welcome Packet. Since SPARK is an online study, participants choose which measures to complete and at what time. Therefore, any given participant may have different phenotype data available.

This document provides further information on recruiting SPARK 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 SPARK families to participate in my research project?
If you want to recruit families as research participants, you will need to follow the new recruitment study process as detailed below. Please note that you will need place a separate request and receive SFARI approval for access to phenotypic and/or genetic data.

If you would like to access recruited participants’ de-identified SPARK data and link to the data you collect in your new study, you will need to include authorization language (bi-directional data sharing language) in your study’s consent form(s). Please work with the SPARK Recruitment Liaison to ensure you will be able to access the data.
Overview: Recruiting SPARK participants

Investigators interested in conducting research studies with SPARK families can initiate a new recruitment study request through SFARI Base.

The process for placing a new recruitment study request is detailed on the SFARI.org resources page.

Briefly, 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.

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 SPARK 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 SPARK Recruitment Liaison. You will be asked to sign the Researcher Recruitment Agreement (see Appendix C], which details SPARK’s policies and procedures for new recruitment studies. You may also need to provide other documentation (e.g. recruitment materials).

4. In order to launch your new recruitment project, you will work directly with the SPARK Recruitment Liaison and our information technology team regarding the timeline and other recruitment project details. SPARK will contact each family to obtain permission 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. Please note that authorization to contact SPARK participants is limited to only the approved study.

5. Contact families to obtain their consent to participate in your study.

6. In the same secure online portal through which you obtained the contact information, enter the 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 SPARK Recruitment Liaison will work with you to define which fields need entry for your particular study.

7. The secure online portal will make available to you the SPARK Publishable ID (SP_ID) only for participants who consented into your study. The SP_ID will allow you to identify the family in the SFARI Base dataset and link to the participant’s phenotype and genetic data.
Frequently asked questions

1. How do I submit a request to recruit SPARK families as participants in my research project?
   Create your request and submit your project documentation for access to SSC resources on SFARI Base.

   See here the SFARI Base resources page 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/or the SPARK Recruitment Access Committee, and we will communicate with you regarding its status (approve, deny, or additional questions). The SPARK Recruitment Access Committee meets once per quarter, but we may do an initial review of your application and ask you some questions in advance of that meeting. It is not usually possible to expedite a new recruitment study request, so please consider the quarterly meeting timeline when planning your project. If you want to check on the status of your application, please contact collections@sfari.org.

   Note: SPARK clinical sites may be eligible for fast-track application status, if the project will only recruit the site’s own affiliated participants. Email collections@sfari.org for questions specific to SPARK clinical sites.

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 is 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 (e.g. 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 PIs. Typical time from approval to launch is between 2 to 6 months, but actual timeline may be shorter or longer.

5. When can I expect to receive the families’ contact information?
   The contact information will start to be available to you as soon as the first participant authorizes, following launch of your new recruitment project. You will be able to pull this information from the secure portal as often as you wish.
6. **What options do I have for new recruitment study workflows?**

   You should discuss the specifics of your project with the SPARK Recruitment Liaison, but SPARK has the ability to support many different kinds of research. Briefly, your options could include:

   a) SPARK can contact participants and ask them complete an authorization to share their contact information with you. Then your lab staff can contact the participants to discuss the study and consent them directly. This is often the option preferred by in-clinic projects.
   
   b) SPARK 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) SPARK 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 SPARK 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 or difficulties uploading forms, any questions about the fields in the new recruitment study application, and/or questions about the status of your application.

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

   A SPARK participant must consent for you to link their SPARK data and recounting data before we can provide you with this information. *If you wish to link data from your project and the SPARK study, you must include the bidirectional data sharing language (see example below) in your consent form in order to receive the identified data. This language must be approved by both the SPARK Recruitment Liaison and your institutional IRB.* Failure to follow this step in its entirety may result in you being unable to obtain the SPARK 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 SPARK) or allow you to enter consent status for each participant. Once you indicate that a family has consented to participate in your study, and thus agreed to the bidirectional data sharing language, we will be able to show you the SP_ID linked to the temporary Recruitment ID. You will be able to use the SP_IDs to obtain the SPARK data. The SPARK Recruitment Liaison can explain this process in more detail.

9. **How do I find a list of research projects using SPARK data?**

   You can locate a list of research projects using SPARK data on SFARI Base [SFARI Base Ordering](#). Log in using your username and password. Click on “Learn About SFARI Base” in the menu, and then click on the “SFARI Base
Projects” link. Selecting the filter for “SPARK” at the top of the page lists research projects using SPARK data. SFARI-funded projects are also listed on sfari.org.

10. 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 (Appendix A and B). You will work with the SPARK 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): consent for you (Researcher) to receive linked, identified phenotype and/or genetic data from the SPARK database using the participant’s SP_ID AND consent to transfer participants’ data from your study into the SPARK database. You must receive approval from the SPARK 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 SPARK 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 language, and recruitment email.

11. 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 SPARK on the participants in your study. This data is shared using a linked ID number (SP_ID) that is not provided until participants consent into 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 SPARK, for inclusion in the SPARK database, in order to continue to enhance this resource. Suggested language is provided below. Please allow your SPARK 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 SPARK to share identified data with you.

“(If study contains non-SPARK participants, start with: For those individuals who participated in the SPARK study,) we are asking your consent for the SPARK study, hosted by the Simons Foundation, to share with [University] the clinical, demographic, and genetic data collected during your participation in SPARK. 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 this study here at [University] with SPARK in order to add to the information}
that was collected during your participation in the SPARK. Please note that both SPARK and this study will also be able to share and link any future data you may contribute to either project.”

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

12. **What is the process for data sharing with SPARK?**
   Once a participant has completed your study consent form (agreed to bi-directional data sharing) and you have the SP_ID for a participant, you will be able to link to the data in the SPARK database.

   You will also be required to share data from your study back with SPARK, to enhance the SPARK database. This will include participation data as well as study-specific data. SPARK will work with you on the terms of this data sharing, but in general the expectation is that data will be made available for SPARK to distribute to researchers publicly upon publication or within 2 years of the end of data collection, whichever comes first.

13. **Is there a fee for SPARK’s recruitment services?**
   At this time, SPARK does not charge a fee. However, this policy may change in the future, in which case documentation will be provided/updated.
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 authorizations, scripts, and emails (Please use the templates below.)

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 SPARK Recruitment Liaison after project approval:
- Signed Researcher Recruitment Agreement (see Appendix C)

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

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 SPARK 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 consent participants in order to receive additional information.

• Data transferred as a result of an authorization CANNOT be used for research unless/until the individual(s) in question is 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.

• For every individual, including other family members, for whom you want SPARK data, you must have consent, authorization or some other IRB-approved process in place. Make sure to have a strategy to obtain all identified SPARK data that you need for your analysis. Discussion with the SPARK Recruitment Liaison if you have questions about this process.
Appendix A - Email Templates

Recruitment Project Email Templates

Initial email template for SPARK Recruitment Studies

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.

Invitation Email with Link

Subject: [Customized to fit project. Examples include: “Invitation: Research Study from SPARK Researchers” or “New research opportunity from SPARK” or “New study recruiting SPARK participants”]

Dear SPARK Participant,

When you joined SPARK, we promised to inform you about research projects that might be of interest to you and your family. Below is an invitation from a team of researchers seeking SPARK families to participate in a new study. Contact SPARK at SPARK@sparkresearchmatch.org if you have any questions about this research invitation.

STUDY NAME: Customized to fit the project

Dear Parent,

Email will briefly describe the research opportunity, what it involves, and if there is any 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

This section thanks the family for their attention, etc.

Sincerely,
Researcher’s Name
Institution
Reminder email template for SPARK Recruitment Studies

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.

Invitation Email with Link

Subject: [Customized to fit project. Examples include: “Invitation: Research Study from SPARK Researchers” or “New research opportunity from SPARK” or “New study recruiting SPARK participants”]

Research Study Opportunity Still Available.

STUDY NAME: Customized to fit the project

Dear SPARK Participant,

When you joined SPARK, we promised to inform you about research projects that might be of interest to you and your family. Below is an invitation from a team of researchers seeking SPARK families to participate in a new study. Contact SPARK at SPARK@sparkresearchmatch.org if you have any questions about this research invitation.

Dear Parent,

Email will briefly describe the research opportunity, what it involves, and if there is any 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

This section thanks the family for their attention, etc.

Sincerely,
Researcher’s Name
Institution
Appendix B - Authorization Template

Recruitment Project Authorization Online Screens for SPARK

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.

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 SPARK study. You may also choose to withdraw your participation at any time.

Eligibility Questions:

For most studies, families will be eligible based on their SPARK 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).

Participation/Authorization Section:

Please note that SPARK is serving as a resource linking SPARK 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 SPARK. Please note: This study is being performed by [NAME OF INSTITUTION]. It is not endorsed by or performed under the auspices of SPARK.

[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 SPARK 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 SPARK so the SPARK team will know how many families were interested in, started, and actually completed the study.

and

2) SPARK to release the information listed below for [designated family members such as PARENT, PROBAND, SIB1] 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 SPARK. (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
- SPARK ID Number
- Mailing Address
- Email address
- Phone Numbers (home, work, or cell) and preference regarding which number researchers should call
- Gender
- Date of birth
- 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 SPARK 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 SPARK 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, SIB, 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. A copy of this form will be available in your SPARK Dashboard.