



User Guide

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1. Introduction

SFARI Base is a clearinghouse for autism and autism-related research data and biospecimens supported by the Simons Foundation Autism Research Initiative (SFARI), as well as an online portal for the submission of research recruitment requests. It contains data from the following cohorts:

- Simons Simplex Collection (SSC)
- Simons Variation in Individuals Project (Simons VIP)
- Simons Foundation Powering Autism Research for Knowledge (SPARK)
- Autism Inpatient Collection (AIC)

Researchers can request access to phenotypic, genetic or imaging data; order biospecimens; and/or submit a research-match application to recruit individuals or families for future research studies.

As additional features are added to SFARI Base, this document shall be updated.

2. Scope

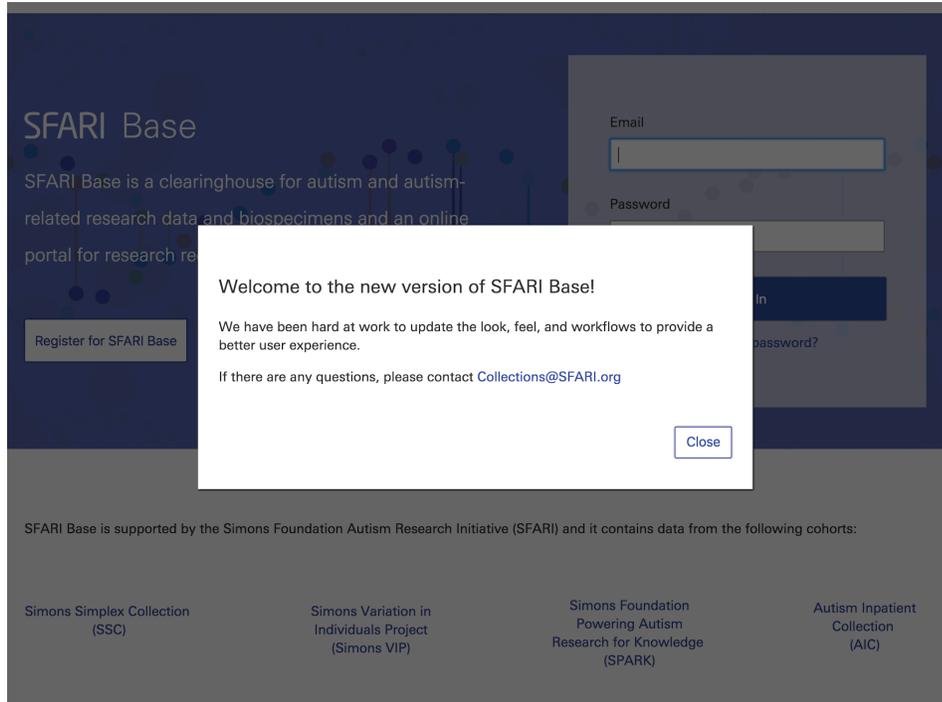
The use of SSC, Simons VIP and AIC data and biospecimens is limited to projects related to advancing the field of autism and related neurodevelopmental disorder research. SPARK phenotypic and genomic data does not have this limitation. Applications will be reviewed to ensure the use of data and biospecimens is in compliance with the Institutional Review Board (IRB)-approved consent language.

Each Principal Investigator must apply to use data on SFARI Base and be approved in order to qualify for access to the SFARI Simons Collection resources. Approved investigators are prohibited from sharing access or distributing data to any other researcher without prior SFARI approval.

Additional SFARI Base Terms and Conditions can be accessed [here](#).

3. Accessing SFARI Base

3.1. Creating an account



All users will be greeted with a brief welcome message, introducing them to the new version of SFARI Base. This window can be closed and users can proceed to selecting “Register for SFARI Base.”

Create a new account

First Name

Last Name

Email

Confirm Email

Password

- ✓ At least 10 characters long
- ✓ Contains at least one number
- ✓ Contains at least one capital letter and one lower case letter
- ✓ Contains at least one special character

Confirm Password

Institution Name or EIN

I agree to the Terms and Conditions

[Create Account](#)

Already have an account? [Log In.](#)

Principal Investigators must provide all information on the account-creation page. As part of account creation, they will need to affiliate with an institution. If the institution is not registered on SFARI Base, they will be prompted to provide institution details as part of registration (Section 3.2).

Principal Investigators will receive an email to verify their email address. After verifying their email address, they can use their email and password to log in to SFARI Base (Section 3.3).

3.2. Creating an institution

If an institution is not registered on SFARI Base, new Principal Investigators will be prompted to provide institution details as part of registration.

Finish Creating Your Account.

Institution Name

Provide the following details about your SFARI Base Signing Official [?](#)
First Name

Last Name

Email

Phone Number (optional)

[Need Help? Contact Us.](#)

Principal Investigators must provide the institution name and SFARI Base Signing Official (SBSO) details (name and email address). The SBSO is an individual with institutional authority to represent their institution in a legal agreement, similar to a material transfer agreement. The SBSO will be expected to:

- provide basic information about their institution,
- confirm any new researchers seeking to affiliate with their institution in SFARI Base, and
- annually review the list of researchers affiliated with their institution in SFARI Base.

The Simons Foundation will follow up with the SBSO, sending a request to create an account within SFARI Base. The institution will appear as “unconfirmed” in SFARI Base; however, Principal Investigators will be able to submit SFARI resource requests and use certain features.

Institution Details

Provide the following details about your institution.

Common Name ⓘ

Legal / Official Name ⓘ

EIN or Institution ID ⓘ

Institution Type ⓘ

Non-Profit

For-profit

Upon verifying their account and logging in to SFARI Base, the SBSO will be expected to provide details about the institution. Upon submitting, a SFARI Base Administrator will be notified to review and confirm the information for the institution.

Once the institution is confirmed and a request for resources has been approved for the Principal Investigator, the Researcher Distribution Agreement (RDA) process will be initiated.

3.3. Logging in

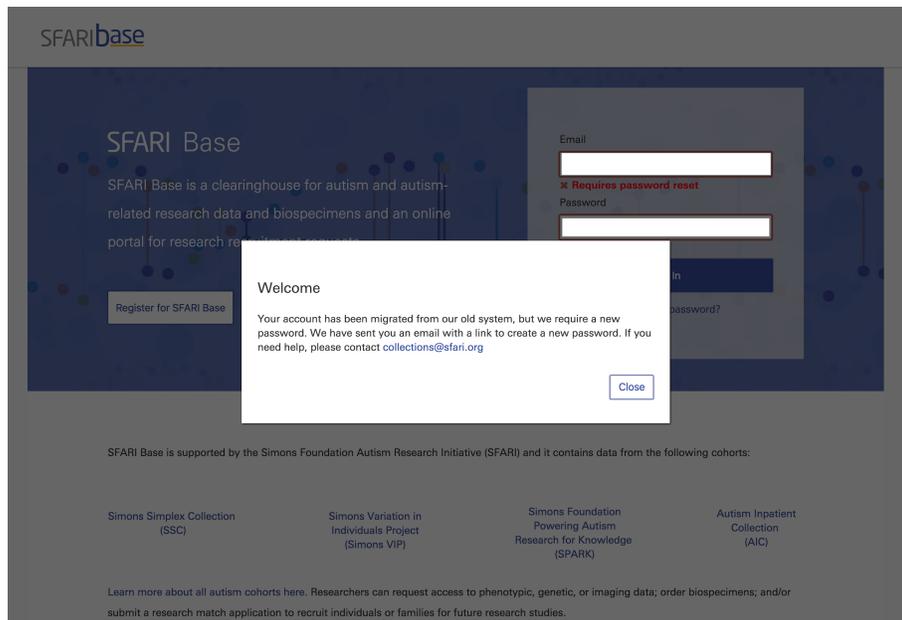
3.3.1. New users

Users (Principal Investigators and SFARI Base Signing Officials) will be able to log in with their email address and password created during the registration process after verifying their email.

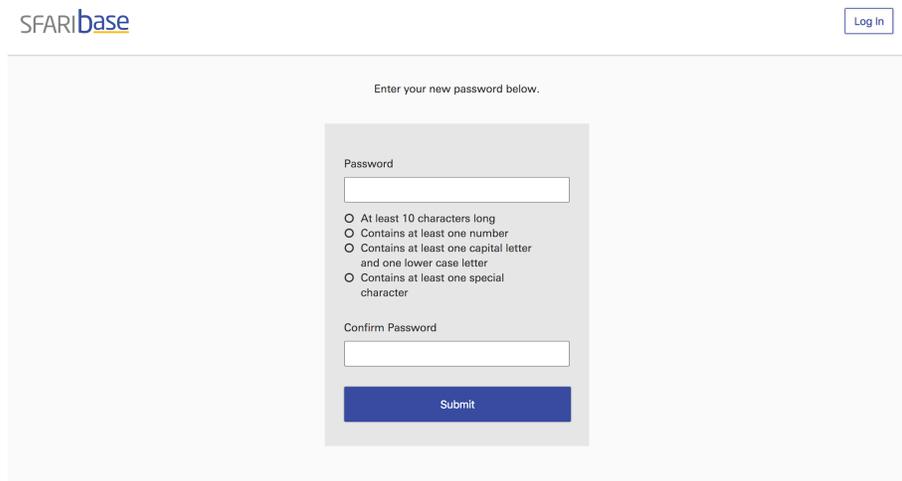
If an RDA has been executed for their institution, Principal Investigators will be prompted to agree to the Joinder to the RDA. If an RDA has not yet been executed, Principal Investigators can submit a request. The RDA process will be initiated once their request for resources has been approved by a SFARI Reviewer.

3.3.2. Migrated users

A migrated user in SFARI Base is defined as a Principal Investigator that had access to a legacy version of SFARI Base. These users accessed SFARI Base by logging in using their 'S.F. ID.' This approach is no longer supported, and Principal Investigators will be able to attempt to log in using the email address associated with their legacy SFARI Base account.



Migrated users will receive a message stating that their account has been migrated, and they will be prompted to create a password to access the new system. This is applicable to both Principal Investigators and SFARI Base Signing Officials.

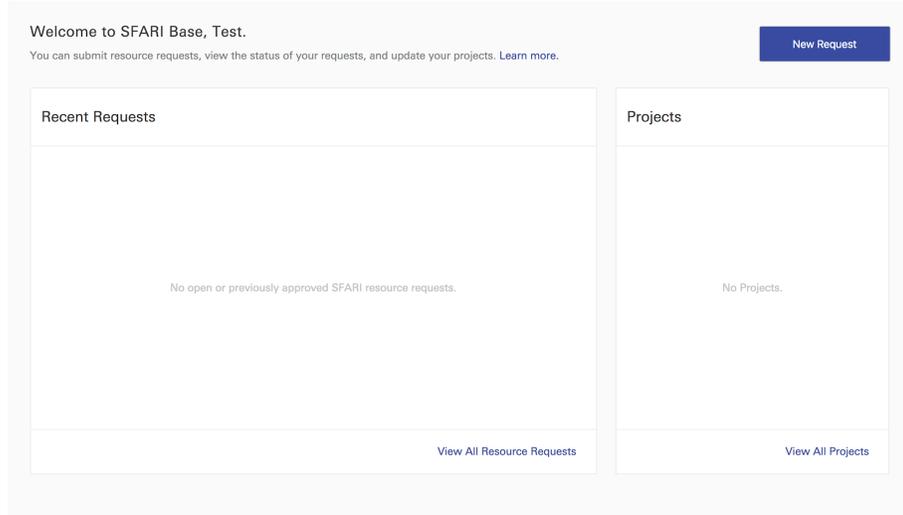


Users should reset their password, ensuring that the password meets the criteria on the screen.

4. Requesting SFARI resources

4.1. Navigating SFARI Base

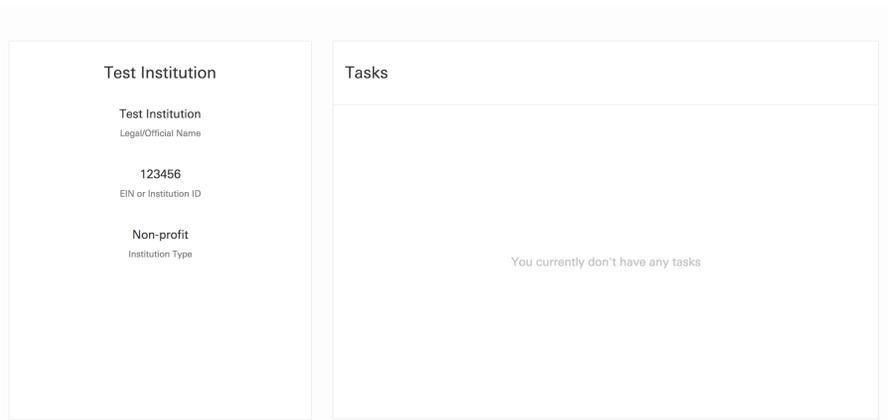
4.1.1. Principal Investigators



Upon logging in, Principal Investigators will see their homepage. On their homepage, they can submit a new request or view their previously submitted requests and projects.

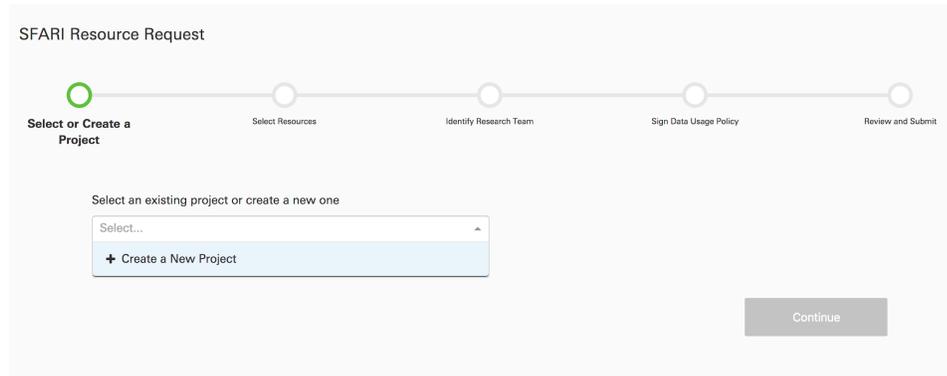
Selecting "New Request" will move the Principal Investigator into the request workflow.

4.1.2. SFARI Base Signing Officials



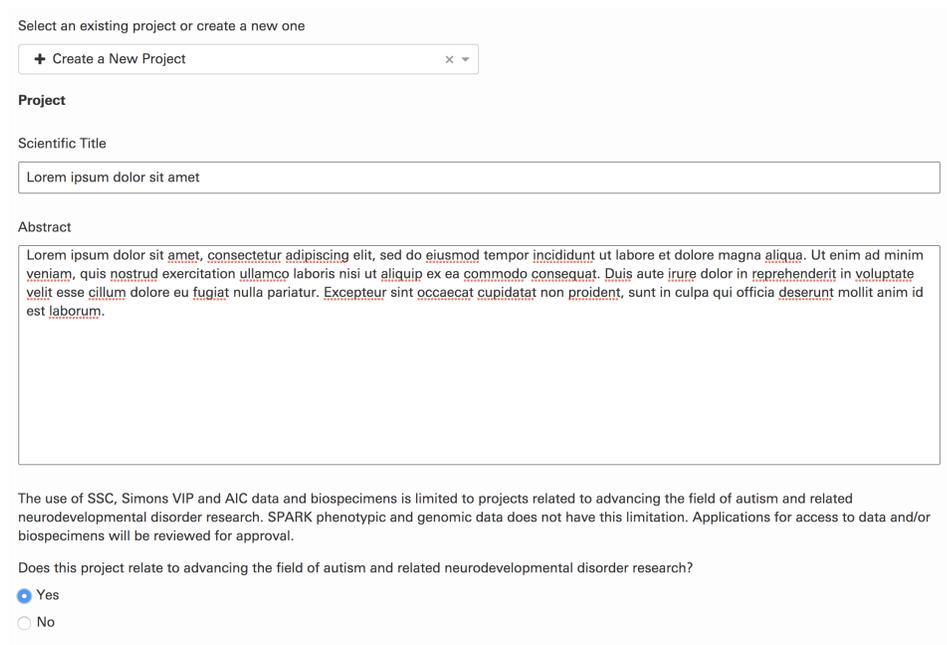
Upon logging in, SFARI Base Signing Officials will see their homepage. If there are any tasks that need attention (such as signing the RDA), they will be informed on the page.

4.2. Selecting or creating a project



The image shows a progress bar for the SFARI Resource Request process with five steps: 'Select or Create a Project' (highlighted with a green circle), 'Select Resources', 'Identify Research Team', 'Sign Data Usage Policy', and 'Review and Submit'. Below the progress bar is a form snippet with the heading 'Select an existing project or create a new one'. It features a dropdown menu with 'Select...' and a '+ Create a New Project' option. A 'Continue' button is located to the right of the dropdown.

Principal Investigators are required to create a project within SFARI Base as part of the request workflow. If a project has previously been created, it can be selected.



This image shows a detailed view of the 'Select an existing project or create a new one' form. It includes a dropdown menu with '+ Create a New Project' and a close button. Below this are fields for 'Project', 'Scientific Title' (containing 'Lorem ipsum dolor sit amet'), and 'Abstract' (containing a large block of Lorem Ipsum text). At the bottom, there is a question: 'Does this project relate to advancing the field of autism and related neurodevelopmental disorder research?' with radio buttons for 'Yes' (selected) and 'No'.

Principal Investigators are required to complete all information on the form before proceeding. This includes whether or not the Principal Investigator would like the Scientific Title and Abstract above to also be the General Audience Title and Abstract. Principal Investigators are given the opportunity to provide a General Title and Abstract. All projects with approved SFARI Resource Requests will be displayed publicly on SFARI.org.

4.3. Selecting resources to request

The resource selection page can be organized by resource or by cohort using the filter.

SFARI Resource Request

View by Resource Type x ▾

Biospecimen

- Genetic Data
- Imaging/EEG Data
- Phenotype Data
- Research Match

SFARI Resources

Biospecimen

- Lymphoblastoid Cell Line DNA
SSC, Simons VIP [More Info](#) [Select](#)
- Saliva DNA
SSC, Simons VIP [More Info](#) Limited Availability [Select](#)
- Whole Blood DNA
SSC, Simons VIP [More Info](#) Limited Availability [Select](#)

Selected Resources

No resources selected

[Continue](#)

[< Previous](#)

SFARI Resource Request

View by Cohort x ▾

AIC

- Simons VIP
- SPARK
- SSC

SFARI Resources

AIC

- AIC Dataset
[More Info](#) [Select](#)

Simons VIP

- Simons VIP Non-familial Control Dataset
[More Info](#) [Select](#)

Selected Resources

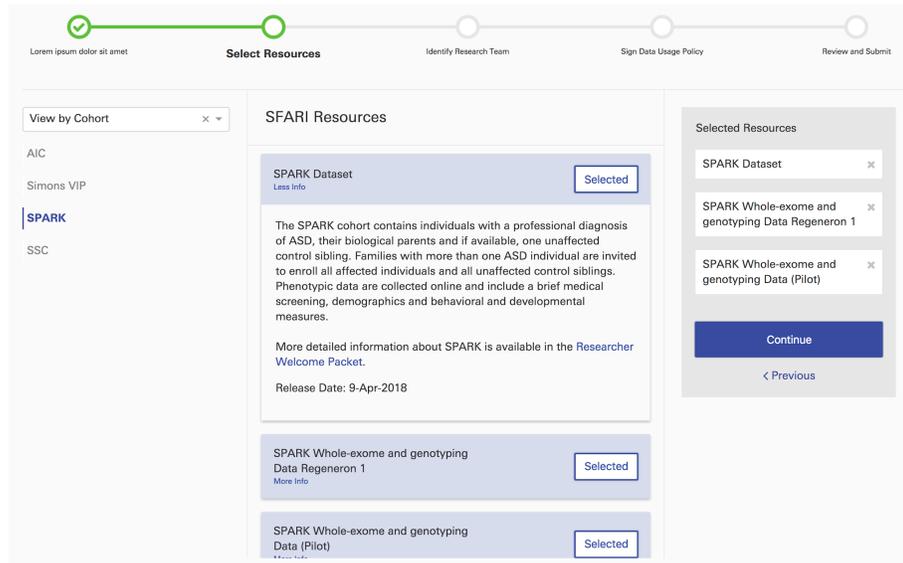
No resources selected

[Continue](#)

[< Previous](#)

Selected resources will be displayed on the right-hand side of the screen as they are selected. For phenotype, imaging and genetic data, multiple resources can be submitted as part of one request. Biospecimens and research-match applications must be submitted one at a time.

4.3.1. Phenotype, imaging and genetic data



Principal Investigators can select “More Info” to expand the selection and see more information about the selected resource.

Selected Resources - SPARK Dataset, SPARK Whole-exome and genotyping Data Regeneron 1, SPARK Whole-exome and genotyping Data (Pilot)

IRB/Institutional Assurance

Please note that the IRB approval or exemption letter /Institutional Assurance Letter is a document signed by your institution assuring that the project is in compliance with laws, policies and regulations indicating that it meets research standards.

What is the status of the IRB/Institutional Assurance approval?

- Approved Project
- Exempt Project

IRB/Institutional Assurance Letter (.pdf only)

No File Selected

Globus Account ID

Select genetic and imaging files will be accessed via Globus, which is used to make storage more accessible to researchers. Please provide your Globus Account ID. If you do not have a Globus Account ID, please create one at globus.org. Your Globus Account ID is the username for your account at globus.org. The correct ID is required in order for the Simons Foundation to provide access to the resources you have requested.

Globus Account ID

IRB/institutional assurance and Globus account information are needed for genetic and imaging requests.

4.3.2. Biospecimens

DNA Details

DNA Amount in micrograms (Minimum criteria for Whole Blood, saliva or Lymphoblastoid Cell Line DNA: 2 ug. Standard criteria: Whole Blood DNA: 5 ug; Lymphoblastoid Cell Line DNA: 5-10 ug; Saliva DNA: 2 ug)

DNA concentration in nanograms per microliter

SFARI IDs

Enter SFARI IDs (e.g. 11000-p1, 11000-mo, 14710-x1)

Request Specifications

Describe what the samples will be used for.

If submitting a biospecimen request, Principal Investigators are required to provide all information that is requested on the form. The information needed is different for each biospecimen type.

For all biospecimen request types, the following information is needed:

- SFARI IDs
- Description of use for the requested biospecimens
- Type of analysis/genetic sequencing that will be performed (with exception to Plasma)
- Funding information
- Shipping address
- Name of individual responsible for receiving the shipment
- Email address of individual responsible for receiving the shipment
- Phone number of individual responsible for receiving the shipment
- Additional Instructions

For Lymphoblastoid Cell Line DNA, Saliva DNA and Whole Blood DNA requests, the following information is needed:

- DNA amount in micrograms
- DNA concentration (in nanograms per microliter)

For Plasma requests, volume in microliters is needed.

For Fibroblasts, information about whether or not the Principal Investigator plans to generate iPS cells is needed.

For Lymphoblastoid Cell Line requests, the following information is needed:

- Request type
- Whether or not the Principal Investigator plans to generate iPS cells

4.3.3. Research match applications

When submitting a research match application, the following data points are needed:

- General-audience title and summary
- Scientific/technical title and abstract of study
- Category and up to three keywords
- Cohort that will be used for the study
- Appropriate description for the study
- Geographical region(s) for recruitment
- List of any standardized instruments
- Inclusion and exclusion criteria for participants
- Desired number of participants for final sample size
- Justification for your sample size and/or participant characteristics
- Incentive or feedback approach for participants
- Any logistical or additional important information to be considered as part of the application
- Source of funding (If SFARI or CRA, the award number is necessary.)
- Proposal summary (PDF upload)
- Full institutional review board (IRB) protocol (PDF upload)
- IRB-approved consent form(s) (PDF upload)

4.4. Research team

SFARI Resource Request

Selected Resources - SPARK Dataset, SPARK Whole-exome and genotyping Data Regeneron 1, SPARK Whole-exome and genotyping Data (Pilot)

The Simons Foundation requires the names, roles, and email addresses of laboratory members that will be accessing the resources requested. This access is restricted to Post-Doctoral researchers and designated managers (laboratory or project managers for example) and does not include graduate students. Co-Investigators or Collaborators at other institutions must also be provided. They will also need a SFARI Base account and approval.

Will there be other individuals who will access the requested resources?

- Yes, there will be other individuals accessing the requested resources.
- No, I will be the only individual accessing the requested resource.

< Previous Continue

Research team information is needed if the Principal Investigator has other individuals that will be accessing the requested resource.

4.5. Data-usage policy

SFARI Resource Request

Selected Resources - SPARK Dataset, SPARK Whole-exome and genotyping Data Regeneron 1, SPARK Whole-exome and genotyping Data (Pilot)

Before placing your dataset or biospecimen request, please review and demonstrate that you understand the following policies by indicating whether the associated statements are true or false:

Access to Datasets and Biospecimens
Limitations imposed on SFARI by research participant consents restrict the use of datasets and/or biospecimens to:

Be used exclusively for the advancement of biomedical science and in a manner consistent with the goals and policies of the Foundation. The requesting Principal Investigator, who shall be responsible for retaining control over all datasets and/or biospecimens obtained from the SFARI Simons Collection and shall not provide, resell, share, or otherwise distribute them (free of charge or otherwise), directly or indirectly, to any other Person other the Principal Investigator, as detailed in the [Researcher Distribution Agreement](#)

Principal Investigators shall be responsible for communicating immediately with a SFARI Research Liaison if they become aware of a breach in policy. If a researcher breaches this policy, he/she may have access to biospecimens revoked. A breach of consent shall also be filed with the appropriate IRB.

Please answer the following question: Approved Principal Investigators must not share access or distribute datasets and/or biospecimens to any other researchers without prior SFARI approval.

- True
- False

The data-usage policy must be answered to show understanding of the policies governing the access and use of SFARI data and biospecimens.

4.6. Review and submit the request

SFARI Resource Request

Principal Investigator & Project

| | | |
|------------------------|------------------|----------------------------|
| Principal Investigator | Institution | Project |
| Test User | Test Institution | Lorem ipsum dolor sit amet |

Resource(s) [Edit](#)

SPARK Dataset
SPARK Whole-exome and genotyping Data Regeneron 1
SPARK Whole-exome and genotyping Data (Pilot)

Research Team [Edit](#)

No team members selected.

[< Previous](#) [Submit](#)

A review screen will be shown before submitting the request.

5. Accessing request details

SPARK Dataset

[Summary](#) [Access Details](#) [Request Details](#) [Data Usage Policy](#)

| | | |
|---------------|----------|-------------------------------------|
| SPARK Dataset | Approved | View Access Details |
| Resource | Status | |

| | |
|------------------|-------------------|
| Resource Details | SPARK Dataset |
| Project | asdf |
| Institution | Test Institution |
| Date Submitted | November 26, 2018 |

Once approved, Principal Investigators can access request details directly through their dashboard. Selecting an approved request will bring the PI to the details of the request. Selecting “View Access Details” will bring the PI to an additional screen where they can download the phenotype data set or access the details of the genetic or imaging data set.