SFARI Base
SPARK

Researcher Welcome Packet

Last Updated: Friday, Jun 25, 2022

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SPARK Participation Criteria

The Simons Foundation Powering Autism Research for Knowledge (SPARK) aims to recruit, engage and retain a community of 50,000 individuals with ASD and their family members. SPARK families enroll online at www.SPARKforAutism.org, provide saliva samples for genetic analysis and agree to be contacted for future research opportunities.

The phenotypic data currently available include basic family and medical history information and choice standardized measures; all are detailed in the table below. Clinical lab results also are available on a subset of individuals who underwent clinical confirmation and have had their genetic results returned to them.

Inclusion Criteria

Diagnostic information
- All individuals with a professional diagnosis of ASD can participate.
- ASD includes DSM-V Autism Spectrum Disorder, and DSM-IV Asperger Disorder, Autistic disorder, Rett Syndrome, Childhood Disintegrative Disorder and pervasive developmental disorder-not otherwise specified (PDD-NOS).

Age
- Individuals of all ages are welcome to participate in SPARK (infants enrolled under 15 months of age are considered at risk of ASD and will be followed over time).

Family members
- Parents and full or half- biological siblings can participate in SPARK (multiplex families may include multiple, unaffected biological siblings).
- Adoptive parents who are legal guardians of children or adults with ASD are also able to register and answer surveys for their adoptive children - but information will not be collected on them

Exclusion Criteria

Residence
- Only residents of the United States can participate in SPARK at this time.

Language
- Participants must be able to read and understand English.

Family members
- Only full biological family members participate in SPARK biospecimen collection.

SPARK Measure Table

Instrument Name and Publisher	Measure Format	Measure Description	Administrations available by role
Area Deprivation Index Kind AJH, Buckingham W. University of Wisconsin School of Medicine and Public Health, 2019	Systematically generated based on parent/guardian/ self-report of physical address	Rank of socioeconomic disadvantage by neighborhood	All SPARK participants
Background History Questionnaire-Adult SPARK	Online, self-report	Demographics, treatment, and social history	Independent ASD Adults
Background History Questionnaire-Child/Dependent SPARK	Online, parent/guardian report	Demographics, treatment, and social history	ASD children Dependent ASD Adults
Background History Questionnaire-Sibling SPARK	Online, parent/guardian report	Demographics, treatment, and social history	Non-ASD siblings <18 years
Basic Medical Screening Questionnaire SPARK	Online, self or parent/guardian report	Medical history	All ASD individuals Non-ASD Parents Non-ASD Siblings
Child Behavior Checklist for ages 1.5 to 5 years (CBCL/1-5) ASEBA	Online, parent/guardian report	Problem behavior	ASD children, 1.5-5 years
Child Behavior Checklist for ages 6 to 18 years (CBCL/6-18) ASEBA	Online, parent/guardian report	Problem behavior	ASD children, 6-18 years
Developmental Coordination Disorder Questionnaire (DCDQ) B.N. Wilson	Online, parent/guardian report	Motor Delays	ASD children, 5-15 years at time of administration

Social Communication Questionnaire (SCQ) – Lifetime WPS	Online, parent/guardian report	Screen of ASD markers	ASD children, 2-17 years 11 months Non-ASD siblings, 2-17 years 11 months
Repetitive Behavior Scale- Revised (RBS-R) Bodfish	Online, parent/guardian report	Repetitive behaviors	ASD children, 3 years and older Dependent ASD adults
Vineland Adaptive Behavior Scales-3rd Edition (VABS-3) Pearson Assessments	Online, parent/guardian report	Adaptive behaviors	ASD children Dependent ASD adults

For detailed information on measures including variables and answer choices, please refer to the SPARK Data Dictionary and SPARK Release Notes; included in the SPARK dataset zip drive.

How to access SFARI Base and request SFARI resources

1. Log into SFARI Base [here](#). If you do not have a SFARI Base account, you may create one. As part of account creation, you will need to affiliate with an institution. If your institution is not registered on SFARI Base, you will be prompted to provide institution details as part of registration. This includes the name and email address for a Signing Official who has authority to represent your institution in a legal agreement, similar to a material transfer agreement.

2. Review your institution's executed Researcher Distribution Agreement (RDA) and agree to the joinder to the RDA. The RDA specifies the legal issues pertaining to research data and specimens, and requires approval from the PI's institution. Each PI and collaborator must agree to the joinder agreement to the RDA for their respective institution.

   For institutions that do not yet have an executed RDA, it will be sent to the institutional officer for review and signature upon approval of a request in SFARI Base.

3. Create a SFARI Base project, which includes the title, abstract, and an IRB approval or exemption document. Each SFARI project led by a PI must be governed by a protocol approved or exempted by an IRB. A protocol specifies the regulatory issues pertaining to the research and may include co-investigators at multiple institutions. You will need to obtain a PDF copy of the letter from your IRB approving or exempting your protocol.

4. Create a SFARI Base request, which includes specifying the type of resource you would like to request access to (phenotype, genetic, or imaging data; biospecimens; and/or research match application). The submitted request will be reviewed by the SFARI science team or appropriate committee.

SPARK Sample Consent Form
https://simonsfoundation.s3.amazonaws.com/share/SPARK/SPARK_consent_form.pdf

If you have additional questions, email collections@sfari.org.