SPARK's Mission

The mission of SPARK – an online research partnership involving 50,000 individuals with autism and their families – is simple. We want to speed up research and advance understanding of autism.

What is SPARK?

- A landmark online research partnership designed to facilitate research that speeds up our understanding of the causes of autism and how autism impacts all those affected.
- This first of its kind study will be done entirely online to encourage all in the autism community to participate, with the goal of establishing the largest online autism research cohort.
- SPARK will collect unique information from individuals affected by autism to equip researchers with the information they need to deliver treatment and scientific advances as rapidly as possible.
- SPARK is sponsored by the Simons Foundation Autism Research Initiative (SFARI).

Who is eligible to join SPARK?

The entire autism community is invited to join this national autism research cohort.
- Individuals with a professional diagnosis of autism and their biological family members will be asked to share information about their medical and family history, as well as provide a DNA sample.
- Families and individuals with autism are eligible to join SPARK if the following criteria are met:
  - He/she lives in the United States
  - He/she is able to read and understand English to consent and complete online questionnaires
  - He/she is an independent adult with autism spectrum disorder (ASD), or the biological or adoptive parent or legally authorized representative/legal guardian of a child or dependent adult with ASD. Biological siblings, with and without autism, are invited to join as well.
  - At least one child has received a diagnosis of autism.

Registration and Saliva Collection Process

- Registration can be done entirely online at www.SPARKforAutism.org/JFKPartners in the convenience of your home.
- There is no cost to join SPARK – you will never be asked to donate money as part of this project.
- There is no requirement to join specific studies, only an agreement to be re-contacted about participation in other research projects.
- A key part of SPARK is collecting DNA to “sequence,” or analyze, genes to improve our understanding of the role of specific genes in the development of autism. This may accelerate drug discovery.
- No blood is needed and you do not have to go anywhere to share DNA. All we need is your saliva.

In appreciation of your participation in SPARK, SFARI will provide a $50 gift card to the individual with autism once your family has returned the saliva sample and completed some medical and family history information.

SPARK will provide support by presenting tips and information about autism and how to approach potential challenges in new and helpful ways.
Research Process

The privacy of SPARK participants is among our top priorities. Information submitted as part of SPARK will be immediately scrubbed of each person’s identity and applied a code to provide the most security possible. Your identifying information will never be shared with any external third parties without your approval.

- Participating individuals with autism, biological parents and siblings will share personally identifying information needed to generate a special code called the Globally Unique Identifier (GUID). By participating in SPARK, you will be allowing SFARI to provide your research data to the National Database for Autism Research (NDAR) using your GUID.
- NDAR is a data repository of autism research by and for researchers from around the country.

Why now?

Autism is known to have a strong genetic component, but there is no singular cause of autism, and there is still so much we don’t know.

Knowledge gained through scientific research like SPARK can be empowering to individuals affected by autism. More research is needed to better understand the causes of autism to develop effective treatments and better tools for the everyday challenges autism brings.

Why do we need your help?

- To isolate insights and potential genetic or other causes of autism, we need large numbers of individuals to power new research. The more participants a research study has, the more confidence we have in any resulting findings proving accurate.
- SPARK will be successful only by collecting a significant amount of data provided by the autism community.
- SPARK researchers are depending on tens of thousands of families and individuals with autism to join this community and provide the data that will help power research aimed at isolating specific genes and/or causes of autism, and translating those findings into real improvements.

How can you join?

There are four steps to complete enrollment:

1. Visit SPARK online at www.SPARKforAutism.org to register. You will be asked to provide your contact information, identify the individual with autism to be enrolled, and create a username and password.
2. Participants will review a consent form. The consent form is important and will explain the details of the study. By signing it, you’ll agree to share the data you provide online and to be contacted for future research studies.
3. You will be asked to tell us a little about your or your child’s autism diagnosis. We will also ask you to tell us a little bit about the other members of your family.
4. In the last step, we will ask you to review a second consent form, in which you will agree to provide genetic data. Unlike other genetic studies in autism, DNA will be analyzed through saliva kits shipped to participants’ homes, making it less intrusive and more convenient for families and adults on the autism spectrum.

Questions?

For more information on SPARK, please visit www.SPARKforAutism.org/JFKPartners.