



Outreach and Recruitment Presentation

Presented on: August 14, 2017

Maine Coalition for Quality Housing and Services

SPARK 
Igniting autism research
Improving lives

The SPARK Study

- An on-line autism research study which involves collecting medical and family histories about individuals with autism and their biological parents and collecting a saliva sample for DNA analysis. This is all done through the mail in the comfort of your home.
- SPARK will connect participants to experts through webinars and on-line materials so they can hear the latest research in autism.
- Each family is given a \$50.00 gift card once registration is completed and saliva samples mailed back.

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.

SPARK Clinical Site Network



- 25 sites selected for a three-year grant with the option to renew each year based on recruitment
- 65% of SPARK participants are affiliated with Clinical Sites
- Sites recruit through their clinics and patient registries, as well as at in-person registration and saliva collection events
- **SPARK Northern New England funded April, 2017**

- **Maine**

- **New Hampshire**

- **Vermont**



Spring Harbor Hospital DD Unit

Center for Autism & Developmental Disorders: Day Treatment & Outpatient Clinic

Autism Research Team

Autism and Developmental Disorders Inpatient Research Collaborative (ADDIRC)

SPARK Northern New England

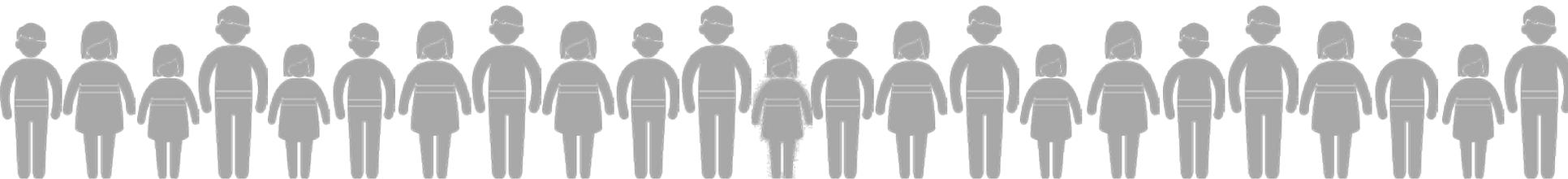


What is SPARK?



- 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 affected¹
- 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 cohort¹

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 sample¹

Families and individuals with autism are eligible to join SPARK if the following criteria are met¹:

- 1 He/she lives in the United States
- 2 He/she is able to read and understand English to consent and complete online questionnaires
- 3 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
- 4 His/her child has received a diagnosis of autism from a professional

Registration and Saliva Collection Process

- Registration can be done entirely online at www.SPARKforAutism.org/mainmedicalcenter in the convenience of your home. While registration will involve a few steps, you can start and stop the process and information will be saved along the way¹
- There is no cost to join SPARK – you will never be asked to donate money as part of this project¹
- There is no requirement to join specific studies, only an agreement to be re-contacted about participation in other research projects¹
- 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 discovery¹
- No blood is needed and you do not have to go anywhere to share DNA. All we need is your saliva. After you sign the consent form, a saliva kit will be shipped directly to you, and you can provide the sample in the comfort of your own home¹



Registration and Saliva Collection Process (Continued)



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 information¹



SPARK will provide support by presenting tips and information about autism and how to approach potential challenges in new and helpful ways¹

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 possible¹

- Your identifying information will never be shared with any external third parties without your approval¹
- Participating individuals with autism, biological parents and siblings, will share personally identifying information needed to generate a special code called a Globally Unique Identifier (GUID)²
 - GUIDs serve as a universal subject ID that allow researchers to share data about you, the study participant, without exposing any of your personally identifying information²
- By participating in SPARK, you will be allowing SFARI to provide your research data to the National Database for Autism Research (NDAR) using your GUID¹
 - NDAR is a data repository of autism research by and for researchers from around the country³
 - Data in NDAR will be kept without names or other identifying information, and will be kept confidential³



Genetic Results

- During registration, participants elect whether or not they would like to be informed of genetic differences that may be identified through SPARK.
- Not everyone who participates in SPARK will have genetic changes known to be associated with autism.
- If you or your child does, and they are identified in the DNA analyses over the month or years following the study, SPARK will return those results to a physician or certified genetic counselor or facilitate access to genetic counseling to discuss the results.
- If you do have genetic results returned to you as a part of this research study, they will become a part of your medical record. Given this, there may be insurance implications you should be aware of. A federal law called the Genetic Information Nondiscrimination Act (GINA) makes it illegal for employers, health insurers and group health plans to discriminate against individuals based on their genetic information.

Why now?



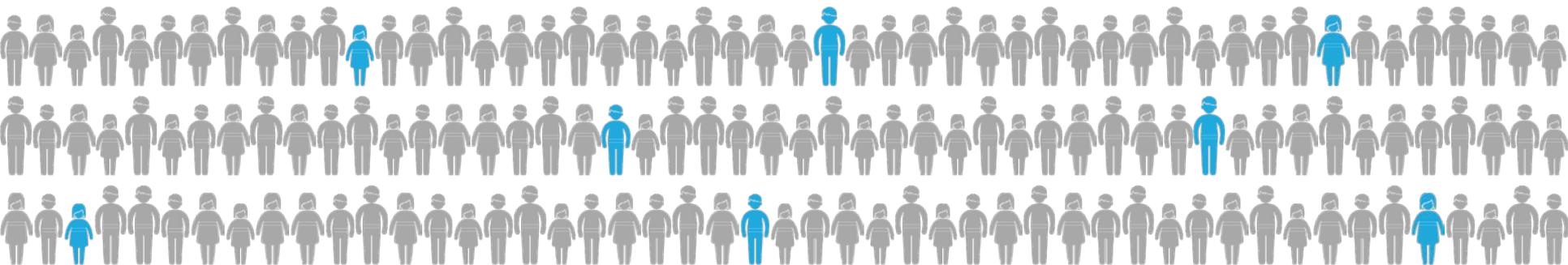
Autism is known to have a **strong genetic component**, but there is no singular cause of autism, and there is still so much we don't know⁴

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



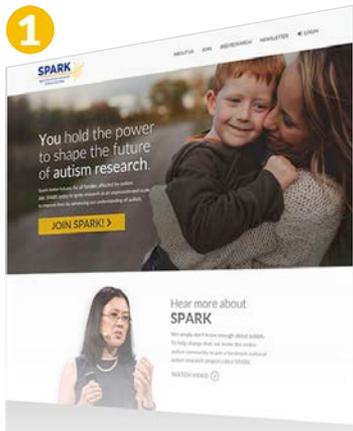
Why do we need your help?



- 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 accurate⁵
- 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 improvements¹

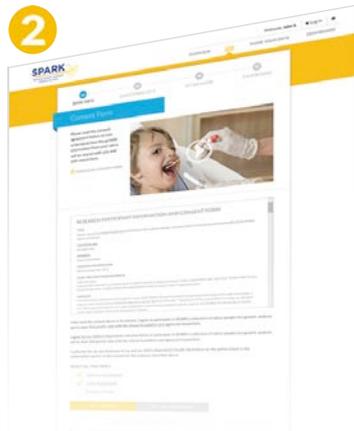
How can you join?

There are four steps to complete enrollment:



First, visit SPARK online at www.SPARKforAutism.org/maine/medicalcenter to register.

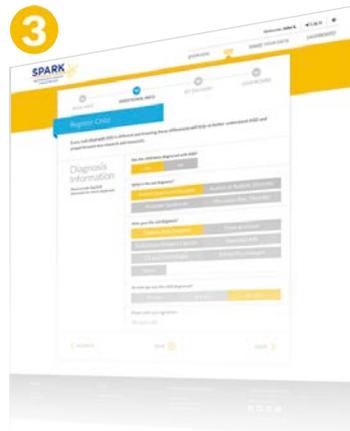
You will be asked to provide your contact information, identify the individual with autism to be enrolled, and create a username and password¹



In the second step, 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 studies¹



In the third step, 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 family¹



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 spectrum¹

- Once consent is provided, saliva kits will be shipped to your family at no cost¹

SPARK Northern New England Team

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Questions?

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Please Visit the SPARK site at:

www.sparkforautism.org/mainemedicalcenter



References

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5. Suresh K and Chandrashekara S. Sample size estimation and power analysis for clinical research studies. *J Hum Reprod Sci*. 2012;5(1): 7-13.