

# SPARK Privacy Policy

Your privacy is very important to us, but it is a shared responsibility. Accordingly, we have developed this policy in order for you to understand how we collect, use, communicate, disclose and make use of Personal Information (as described below).

By using the SPARK Web portal, you signify that you agree with this Privacy Policy. We reserve the right to modify this policy at any time. All modifications to this Privacy Policy will be posted on the Web portal. Your continued use of our Web portal indicates your agreement with these modifications. If you do not agree with this Privacy Policy, please do not provide us with any Personal Information and refrain from using our portal. If you have entered Personal Information, and do not agree with the Privacy Policy, you should delete your account, which will permanently remove your Personal Information from the Web portal and backup database.

## Our responsibilities

- We will protect Personal Information by reasonable security safeguards against loss or theft, as well as unauthorized access, disclosure, copying, use or modification.
- Except as otherwise described in this Privacy Policy, we will not share your Personal Information, unless you give us explicit permission to do so.

## Your responsibilities

- Respect your own privacy. Keep your password safe. Do not share it with anyone.
- Likewise, respect the privacy of others. For example, do not attempt to access another user's account.
- If you learn that your or another's account information has been lost or stolen, or you learn of any unauthorized use, notify us immediately at [info@SPARKforAutism.org](mailto:info@SPARKforAutism.org).
- Correct and update your information as necessary.
- If you are under age 18 or a non-independent adult, use of some portions of the site may require consent from your parent or guardian.

## Nature of the information we collect

SPARK collects information that you provide to us directly or have authorized third parties, such as other research teams or clinical care providers, to provide to us. This information may be collected as part of the registration process to use the services of the SPARK Web portal, or as part of a human subjects research project, in which case you will need to consent to participate. Examples of Personal Information that we collect may include, without limitation, your name, contact information (such as physical address, telephone number and email address), birth date, sex, race, ethnicity, medical diagnosis, treatment and condition information, personal health records, biospecimen data, clinical trial information, and other personally identifiable information. Together such information is referred to as "Personal Information" within this Privacy Policy.

We also collect non-personal information and anonymous information from users, to be used in an aggregate fashion or with certain identifying data removed. For example, we may collect system-related information, such as an IP address, browser type and operating system type to be used for system administration purposes, to help diagnose problems with our servers, to monitor traffic patterns, to determine which services are used most frequently to assess site usage, and for advertising purposes. We may also use cookies to better tailor the portal to users' needs. You can reset your web browser to refuse all cookies or to indicate when a cookie is being sent. Some features of the Web portal may not function properly if the ability to accept cookies is disabled.

## Transmission, storage and security of Personal Information

We have implemented security measures intended to protect your Personal Information, including the use of industry standard data encryption technologies. We also have security measures in place at our physical facilities to help protect against data loss, misuse, or alteration. However, we cannot guarantee the security of any information. All information gathered from you will be stored in the United States, even if you access the SPARK Web portal from a location outside the United States.

## How we use this information

We may use your Personal Information for lawful purposes, including, to determine which research opportunities and article content are most relevant to you, contacting you to participate in research opportunities, authenticating your identity, addressing technical and quality assurance issues, and updating records regarding your account and related purposes. We will also allow you to share your Personal Information with other SPARK participants based on the personal privacy settings you establish.

The SPARK Web portal may openly represent data from you and others in aggregated, anonymous form. We may disclose anonymous, participant-level data to external scientific investigators we deem are qualified, at our sole discretion.

We may also disclose your Personal Information to third parties when we believe, in good faith and in our sole discretion, that such disclosure is reasonably necessary to: (a) enforce or apply our terms of use; (b) comply with legal or regulatory requirements; (c) protect the rights, property or safety of our users; or (d) prevent a crime or protect national security.

Any Personal Information or other content that you voluntarily disclose through the Web portal (such as through a community discussion forum) will be publicly available and can be collected and used by others without any additional permission.

## Children's Privacy

SPARK and the Simons Foundation do not knowingly collect or maintain personally identifiable information or non-personally-identifiable information on the Web portal from persons under 13 years of age, and no part of our Web portal is directed to persons under 13. If you are under 13 years of age, then please do not use or access the Web portal at any time or in any manner. If SPARK learns that personally identifiable information of persons under 13 years of age has been collected on the Web portal without verified parental consent, then SF will take the appropriate steps to delete this information.

## Data retention and withdrawing from participation

We may retain your Personal Information for as long as we deem reasonable and/or as long as the law requires and allows. You may withdraw from participation and delete your account and data from the SPARK Web portal at any time. However, we will not make any attempt to retrieve or delete anonymized data given to third parties — for example, with external scientific researchers.

## Links

We may provide links to other websites and resources ("External Resources") that are not part of the SPARK Web portal. We cannot be responsible for the privacy policies, practices, or content of these External Resources. We encourage you to review the privacy policies and [terms and conditions](#) of such External Resources so that you understand how they collect, use and share your information. Please be aware that this Privacy Policy does not apply to Personal Information collected on websites or other External Resources that may be linked to or through the SPARK Web portal.

## Communications to and from SPARK

**Participation in SPARK:** We have a special registration process for individuals who are interested in participating in the SPARK study. During that registration process, you will be asked for your name and email address. This information is required so that we may recontact you as part of your participation in the study.

**Newsletters** -- If you wish to subscribe to our email newsletter, we will use your email address to send the e-newsletter to you. Out of respect for your privacy, each e-newsletter we provide a link for you to unsubscribe.

**Customer Service** -- Based upon the email address you provide us, we will send you a confirmation email to verify your email address. We will also communicate with you in response to your inquiries, to provide the services you request, and to manage your account. We will communicate with you by email or telephone, in accordance with your wishes.

**Other Features** -- We will use your email only to contact you about the features on our website in which you have expressed interest. You can safely unsubscribe at any time.

**Information Sharing** -- In the course of using this website, you may choose to provide us with information to help us serve your needs. For example, you may send us electronic mail or information via a web form to request information. Any Personal Information you send to us will be used only for the purpose indicated and will not be shared with a third party without your consent. Requests for information will be directed to the appropriate staff to respond to the request, and may be recorded to help us update our website to better respond to similar requests. We will not sell, exchange or otherwise distribute your Personal Information without your consent, except to the extent required by law. We may share your Personal Information with our third party vendors and service providers to provide technical support for the Web portal or other assistance with the SPARK activities and programs. These third parties are prohibited from using your Personal Information for any other purpose. We do not retain the information longer than necessary for normal operations.

If you have any questions regarding this Privacy Policy, please contact us at [info@SPARKforAutism.org](mailto:info@SPARKforAutism.org).