

Frequently Asked Questions

What is the KP Autism Family Biobank?

The KP Autism Family Biobank is a study of Kaiser Permanente Northern California children and young adults with Autism Spectrum Disorder (ASD) and their biological parents. The study seeks to enroll 5,000 affected children plus their parents (for a total of 15,000 participants) to create a collection of genetic material and information for future research. Dr. Lisa Croen is the principal investigator of the study.

The KP Autism Family Biobank is funded by the Simons Foundation, a private foundation whose mission is to advance the frontiers of research to promote a deeper understanding of our world. In 2003, the Simons Foundation launched the Simons Foundation Autism Research Initiative (SFARI) whose mission is to improve the understanding, diagnosis and treatment of autism spectrum disorders by funding innovative research of the highest quality and relevance.

Who is eligible to participate?

Families who are willing to donate a sample of blood or saliva for the child with ASD, the biological mother, and the biological father. The study requires a sample from all three members of the family.

What if I am the main caregiver or legal guardian of a child with ASD, but I am not the biological parent of this child? Can I still participate?

No, at this time we are only collecting blood or saliva from the child and the biological parents.

What does participation in the KP Autism Family Biobank involve, exactly?

The study has two parts: **Blood or Saliva Sample Collection**, and **Survey completion**

Part 1: Blood or Saliva Sample Collection

We would like to collect a sample of blood or saliva from the child affected with ASD, and from both his/her biological mother and father. These samples will be stored for future research about autism. A bank containing 15,000 samples of blood and saliva will be invaluable for scientists studying ASD.

Do I need to provide both blood and saliva?

No, you can choose whether you want to provide a blood sample **or** a saliva sample. We do not need both. The same is true for your child's biological sample. Blood is preferred because it is a source of both genetic and environmental (non-genetic) information.

Why are you collecting blood or saliva from me and my child?

By collecting blood or saliva samples from children with ASD and their biological parents, scientists will be able to conduct important research on ASD that might help us better understand what contributes to the development of ASD, or what treatments might work best for children with ASD.

How do I go about donating a sample?

The first step is for you (a biological mother or father) to log in to the link we provided in the invitation letter (www.autismfamilybiobank.kaiser.org) to consent for the study for yourself and for your child under 18 years, or your adult child who is incapable of giving consent. You will also be asked to choose the type of sample you and your child want to donate. The second biological parent will also have to consent and choose either blood or saliva.

How will I give blood? (Where do I go?)

If you are willing to contribute blood or have your child contribute blood, you will be able to go to any Kaiser Permanente laboratory for a blood draw. You can even combine this visit with other lab work if it is convenient for you.

How long do I have to have to donate blood?

The blood order is only good for 4 months. We encourage you to try to donate it as soon as it is convenient after you sign the consent. The study staff will remind you periodically until you complete the blood donation. After the blood order expires, if you have not managed to donate blood, study staff will mail you a saliva kit to your home.

What do I need to do to donate saliva?

If you are willing to give a saliva sample, or have your child give a saliva sample, you will be mailed a saliva collection kit with a return envelope. The packet will also include collection instructions.

Is one tube of saliva enough?

Sometimes we need to collect a second tube of saliva from children to have enough DNA for our research. If that is the case, we would let the parents know and will mail a second kit for collecting saliva from your child.

What if my child can not spit into the tube?

If select a saliva donation for your child, you will be asked if your child can spit into a tube or if you would prefer to receive an “assisted” saliva kit. The assisted kit makes it easier for a parent to collect saliva from the child.

Do I receive any compensation for giving blood or saliva? Will my child receive any compensation for giving blood or saliva?

Yes, as a token of our appreciation, each participant (you, your child and the other biological parent) will receive a gift card to Amazon.com for \$15 after completing the blood or saliva donation.

How can the other biological parent of my child with ASD give blood or saliva?

If you choose to participate in the study, you will be asked some questions when you log-in to provide the online consent. One of the questions will be whether the other biological parent of your child with ASD may be willing to contribute a blood or saliva sample.

Part 2: Survey Completion

We created an online page for study participants named KP@IAN. After parents consent to participate in the study they will receive an email invitation to register at KP@IAN and answer **two short surveys** that would allow scientists to know more about the family’s health and their child’s ASD. The KP@IAN website will also have information and resources that may be of use to you and your family.

What are the surveys about?

We want to find out more about your family health history, so we are asking one of the parents to complete a brief **Family History Questionnaire**. We also want to know more about you, your child’s, and the other parent’s social interactions, so we are asking both parents to complete the **Social Responsiveness Scale (SRS)**. There are two versions of the Social Responsiveness Scale (SRS). They will give us a better understanding of your family’s activities and how you behave around others.

Parent-Report SRS: We will ask you to answer questions about your child. We want to know about their activities and their behavior around other people including other children and adults outside of the home. The version of the SRS that you will complete should reflect the current age of your child.

SRS Adult Research Version: This is the *Adult Research Version* of the SRS. It needs to be completed by your spouse/partner, if available, or by another adult who knows you well. *It is important that you don't answer questions about yourself.* The questionnaire asks about your interactions with people in social settings. Make sure to ask the person completing the form to please check the box that best describes *your* behavior over the last six months. In addition, please complete an *Adult Research Version* of the SRS for the biological father of the child in the study, if possible. *It is important that he does not answer questions about himself.* Please make sure to check the box that best describes *his* behavior over the last six months.

How long will it take to complete the surveys?

The KP Autism Family Biobank surveys will take approximately 30-45 minutes to complete.

How do I complete the KP Autism Family Biobank surveys?

The surveys are available online at KP@IAN. You will receive an invitation email with instructions and a link to register and complete the surveys. Once you have logged in, you will be asked some preliminary questions and then you will see a consent form. There will be clear instructions about how to navigate the surveys online.

What is KP@IAN?

IAN, located at the Kennedy Krieger Institute in Baltimore, Maryland, is the world's largest online autism research project. IAN collects information from thousands of families affected by autism spectrum disorder (ASD) via online surveys, and matches families to research studies recruiting participants.

KP@IAN is an online community created for the KP Autism Family Biobank that has two sites: an open site that will have autism related articles, webinars, videos, tools and newsletters; and a "closed" site that you will access by registration only. It is in the registration-only site that you will be able to answer the surveys.

How do I register for KP@IAN?

Check your email inbox for an invitation email containing a link to join KP@IAN. That email will also have clear instructions about your registration. Registration is necessary because this is a protected site.

What if I want to complete the surveys, but do not have access to the internet?

If you do not have access to the internet you can still complete the surveys. Please call 866-279-0733 and we will assist you.

Can I stop the surveys in the middle if I have to and return at a later time?

The surveys are short, so we encourage you to start and finish them in one sitting. However, if you need to, you can start the survey and then stop in the middle and come back to it at a later time.

Who will see my answers to questions on the KP Autism Family Biobank surveys?

Access to Kaiser Permanente Autism Family Biobank information is limited to Kaiser Permanente research staff who has signed agreements promising to safeguard your information and to use it only for approved scientific purposes. In addition, the KP@IAN administrators, who are also in compliance with the rules to protect your information, will have access to your surveys and to your email address and first name. They need this in order to invite you to register for IAN.

Also, we will label your survey answers with a unique study number only (we will not include your name, address, or any other information that might identify you). Your unique study number will not be the same as other personal numbers such as your phone number, social security number or medical record number. The link between your medical record number and the study number will be kept secure, with access restricted to a very small number of Kaiser Permanente Division of Research staff.

Do I receive any compensation for completing the surveys?

Yes, once you have completed the surveys you will receive a gift card to Amazon.com for \$15 (one per family) as a token of our appreciation for your participation. Your child's name will also be entered in a raffle for an iPad.

Are there any benefits to participating?

You can help scientists find new ways to prevent, find, and treat ASD. It may help others, such as family, friends, or your community in the future. You should not expect to get direct health benefits from this research.

Are there any risks to participating?

If you choose to participate, unauthorized individuals could possibly access study records, but the security measures we have put in place make that highly unlikely. There are no major risks associated with giving saliva or blood samples.

Will participation in this study effect my medical care or the care my child receives?

This research is not part of your medical care. Your participation is completely voluntary and your decision about participating will not affect the care you or your child receive at Kaiser Permanente.

What are my options regarding participation?

It is important for the study that all three members (child, biological mother, and biological father) participate in the sample donation (Part 1), only the parents will be asked to participate in the survey completion (Part 2). You can choose not to participate. Participation is completely voluntary.

What happens if I decide not to participate in this study?

Your participation is completely voluntary. If you choose not to participate, or if you choose to participate at first but then change your mind, it will not have any effect on the care you or your child receives at Kaiser Permanente. If you decide to stop participating, any information that you provided will no longer be used. No information that you provide will go into your medical record or your child's medical record.

What if I do not want anybody to contact me in the future about this study?

If you do not want anybody to contact you about this study in the future, please call 1-866-279-0733, or send an email to autism.research@kp.org.

Where can I go to get answers to additional questions that I have?

You can go online to AutismResearch.kaiser.org, call the study staff at 1-866-279-0733, or email them at autism.research@kp.org with any additional questions.