UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Brain Imaging and Cell Signaling: Insights into the Biology of Autism

This is a research study. The study doctor Elliott H. Sherr, M.D., Ph.D. from the Department of Neurology and/or a research coordinator will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about your child's participation in this study, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

Your child is being asked to take part in this study because:

1. He or she has been given a diagnosis of Autism Spectrum Disorder (ASD), a similar disorder characterized by social and/or behavioral deficits, or is suspected of developmental delay or he or she is a brother or sister of someone who has been given a diagnosis of ASD or a similar disorder.

   AND/OR

2. He or she has a head circumference that is characterized as macrocephalic, normalcephalic, or microcephalic.

   AND/OR

3. He or she has a particular chromosomal or genetic change. A chromosomal/genetic change is a specific change inside the DNA of a person that may affect their development and/or health.

   AND/OR

4. He or she is a control participant for this study. He/she is the same age and gender of the study participants.

Why is this study being done?

Dr. Sherr and his colleagues at UCSF conduct clinical research seeking to advance the understanding of autism spectrum disorders (ASD) as well as other neurodevelopmental disorders. With these investigations, we are trying to understand how biochemical pathways, brain anatomy, and brain connectivity may affect thinking, behavior and overall development.

How many people will take part in this study?

Approximately 50 people with ASD and macrocephaly or other developmental disorders or genetic changes will take part, as well as 50 matched macrocephalic controls. Approximately 40 people with ASD and normalcephaly or other developmental disorders or genetic changes will take part, as well as 40 matched normalcephalic controls. Approximately 50 people with ASD and microcephaly or other developmental disorders or genetic changes will take part, as well as 50 matched controls. Additionally, 150 parents and approximately 100 siblings will also enroll. Of the 140 ASD individuals, we anticipate approximately 100 individuals will be eligible for the imaging portion of the study.

What will happen if my child takes part in this research study?

If you agree to let your child be in this study, the following may happen:

1. The researchers will gather information about your child from your child's medical record. The researchers will also measure the head circumference of your child and the head circumference of both parents. This can be done at home with our guidance over the phone or in person.
2. You will bring your child to UCSF's Pediatric Clinical Research Center (PCRC) or the UCSF Neurosciences Clinical Research Unit (NCRU) at Mission Bay and your child will give a blood sample. The blood will be drawn by putting a needle into a vein in your child's arm. One to five tubes of blood (10-30mL, approximately one to two tablespoons) will be taken. This will take about five minutes.
3. You and/or your child may be asked if they would like numbing cream to reduce the discomfort associated with the blood draw. The research coordinator will administer the cream 20-30 minutes before the blood draw.
4. You and/or your child may be asked to provide an additional blood sample for further analysis at a later study visit. Approximately 10-20 mL of blood will be collected during each visit for up to two additional visits. The additional samples will not be obtained in the same visit as the first blood donation but would occur at least two weeks apart for each draw. The volume of blood that will be drawn in this study will not exceed 50 mL over an 8 week period. Giving an additional sample of blood is entirely optional.
5. Your child's height, weight, and head size will be measured. Vitals will also be taken.
6. Your child may be asked to complete an evaluation with a psychologist and/or a research team member at the UCSF Pediatric Clinical Research Center (PCRC). This entails a cognitive and behavioral evaluation with an age-appropriate subset of instruments to measure verbal, nonverbal, social-communication and motor development skills. During the evaluation, the researcher will ask your child questions to assess your child's thinking at the time of the test.
7. You will be asked to complete a series of standardized survey measures about your child's social, behavioral, and developmental traits. The surveys will take

about 1 hour to complete, and can be done at home or over the phone with the research staff.

8. You and/or your child may also be asked if you and/or your child would allow the in-person cognitive testing session to be videotaped. Videotaping is used to ensure research reliability in testing administration and accurate scoring of the testing session.

Imaging Project

1. MRI

a. Your child may be asked to undergo a Magnetic Resonance Imaging (MRI) exam without sedation and without contrast at the UCSF Neurosciences Clinical Research Unit (NCRU) at Mission Bay.
b. Your child may be asked questions about symptoms and medical history related to their condition prior to the exam to confirm that they qualify for the study.
c. For the MRI exam, your child will be asked to change into a hospital gown. If your child has removable dentures, an artificial limb or another metallic device, your child will be asked to remove this device temporarily for the test.
d. Your child will lie down on a narrow bed that will be placed in a tunnel 6 feet long by 22 inches wide and open at each end. They will lie there quietly during which time they will hear a loud noise. They will be given earplugs to lessen the noise. They may feel warm during this procedure. Your child will be in frequent communication with the MRI technician and may press a button if you need assistance at any time.
e. Your child will also be asked to take additional pictures (called Diffusion Tensor Imaging or DTI). DTI is an advanced type of MRI, which allows us to see connections of nerve pathways in the brain. The imaging does not require that any needlesticks or medications be given.
f. During the functional MRI exam, your child may be asked to open and close their eyes, listen to sounds, view words or images on a screen, speak or make other intermittent movements. Sometimes, your child may be asked to just look at a picture or listen to a sound; at other times, your child may be asked to look at a picture or listen to a sound and then answer a question by pressing a button. Your child may be asked to rest quietly. None of the stimuli are painful or harmful.
g. Since risks to a fetus from MRI are unknown, pregnant women may not participate in studies involving MRI procedures.
h. The MRI generally takes about 1-1.5 hours.

i. If your child will need to undergo an MRI here at UCSF at the recommendation of their physician, we may ask that additional research pictures for this study be taken during the MRI.

2. MEG

a. Your child may be asked to undergo magnetoencephalography (MEG) testing in the Department of Radiology and Biomedical Imaging at UCSF Parnassus.

b. You will be asked questions about your child's medical history prior to the exam to confirm that they qualify for the study.

c. Your child will be asked to remove any metal items from their clothing, or to change into hospital clothing for the test. If your child has removable dentures, an artificial limb or another metallic device, your child will be asked to remove this device temporarily for the test.

d. An electrical brainwave (EEG) test may be part of your child's exam. For this test, your/ your child scalp will be scrubbed with a mildly abrasive electrode gel, and a number of small discs will be fastened with electrode paste, a sticky material that will be cleaned off at the end of the test. Alternatively, an electrode cap may be used; in this case, your child will be asked to wear a cap, much like a swim cap, that has electrodes sewed into the fabric. Electrode paste will be placed under each electrode using a blunt plastic syringe.

e. Additional electrodes may be taped to measure your child's heartbeat (EKG) and eye movement (EOG). For EKG, the electrodes will be taped in the collarbone or upper back area. For EOG, electrodes will be placed above and below your child's eyes and on each temple. These electrodes will be fastened with paper tape.

f. Your child will be asked to enter the magnetically shielded room (MSR), which contains the MEG instrument. The MSR is equipped with sound and video monitors to allow free communication with the MEG technologists, who generally remain outside the room during the actual collection of data.

g. Three black dots will be marked on your child's skin with a permanent marker: one on the bridge of the nose and one in front of each ear. These dots are used for matching MEG data with MRI pictures. They may be washed off at the end of the MEG session unless your child is scheduled for an MRI within the next day or so, in which case we would ask your child to keep them on.

h. Your child will be asked to lie on a bed or sit in a cushioned, reclined chair. Three head localization coils, encased in rubber, will be taped to the previously marked dots. Other equipment, such as earphones, pneumatic tappers (on fingers, for example), microphones, projection screens, etc., will be set up as needed for each particular subtest. If muscle activity (EMG) will be recorded (e.g., for a motor-related task), three additional electrodes will be placed on the muscle and on

reference points some distance from the muscle. Your child will be positioned with your child's head inside the helmet-shaped MEG sensor which may cover your child's eyes.

i. A noise test will be performed to verify that all removable metal has been removed. While in the sensor, your child will be asked to open and close his/her mouth, to blink his/her eyes a few times, to wave a hand, etc.

j. The MEG exam will generally take 1.5-2 hours. During this period, your child may be asked to open and close his/her eyes, listen to sounds, view words or images on a screen, feel tapping, vibrations or mild electrical stimulation on the skin, speak or make other intermittent movements. Sometimes, your child may be asked to just look at a picture or listen to a sound and; at other times, your child may be asked to look at a picture or listen to a sound and then answer a question by pressing a button. Your child may be asked to rest quietly. None of the stimuli are painful or harmful.

k. At the completion of the MEG exam, the coils, earphones, etc., will be removed. If your child is scheduled to have an MRI within the next day or so, small sections (approx. 1cm x 1cm) of clear Tegaderm tape will be placed over the three black marks. Three Cheerio-shaped reference markers will be placed over the marks during your child's MRI for matching with MEG results. If you are not having an MRI, the black dots will be removed with alcohol swabs. It will usually be the case that the black dots are removed.

Behavioral Training for the Scanner

1. Your child will have the option to participate in behavior training that may help ease any discomfort he or she may feel when lying in a scanner.
2. To help ease any discomfort, your child may practice these training activities at home prior to your visit. The research staff will provide materials and instruction by request. The behavioral training kit includes: a description of the MRI and MEG, a picture book, a CD or a portable media player preloaded with sounds and beeps of the scanners, and instructions on how to practice desensitization training.

How long will my child be in the study?

The research activities outlined above can be completed in 1- 2 visits. The total time required is not expected to exceed 8 hours.

Can my child stop being in the study?

If you first agree to let your child participate and then change your mind, you are free to withdraw your child from the study and discontinue your child's participation at any time. If you choose to tell the researchers why you are leaving the study, your reasons for leaving may be kept as part of the study record. Your decision will not affect your child's ability to receive medical care and your child will not lose any benefits to which your child would

otherwise be entitled. Also, the investigators or other member of the research team may stop your child from taking part in this study at any time if he or she believes it is in your child's best interest, if your child or you do not follow the study rules, or if the study is stopped.

What risks can my child expect from being in the study?

Blood Draw

Drawing blood may cause temporary discomfort from the needle stick. Other risks associated with having blood drawn are slight but may include fainting or feeling light-headed, bruising, and infection. There is also a small risk that your child might feel distressed or nervous about having blood drawn (venipuncture). To reduce the discomfort from the needle stick, your child may be asked if they would like to use numbing cream.

MRI

Standard structural MRI evaluation involves some risk. Because the MRI machine acts like a large magnet, it could move iron-containing objects in the MRI room during the examination and could harm your child. Precautions will be taken to insure that no loose metal objects are in the room; loose metal objects, like pocketknives or key chains, are not allowed in the MRI room. If your child has a piece of metal in his/her body, such as a fragment in your child's eye, aneurysm clips, ear implants, spinal nerve stimulators, or a pacemaker, your child will not be allowed into the MRI room and cannot have a MRI.

There may be some discomfort associated with the MRI procedure, in particular, feelings of claustrophobia and discomfort from the loud banging noise during the study. Participants will be asked to wear earplugs to prevent temporary hearing loss that has occasionally been reported from the loud noise. At times during the test, your child may be asked not to swallow for a while, which can be uncomfortable. Your child can terminate the session at any time by pressing a button.

MEG

No significant health risks associated with MEG or EEG procedures are known. These procedures do not involve injections or radiation exposure. Participation may result in inconvenience, fatigue and/or boredom. Your child might experience some mild discomfort from holding still during data acquisition. All stimuli and tasks will be of a non-painful nature. Your child will always be able to communicate to a technologist through the intercom system at any time. At the completion of your child's MEG session, your child may feel some initial discomfort when tape is removed. Also (if your child do/does not have an MRI exam scheduled in the next day or so), alcohol swabs used to remove the black dots from your child's skin may cause mild irritation.

MEG and MRI

Study researchers may sometimes identify previously unknown abnormalities in MEG/EEG or MRI results. If this occurs, Dr. Sherr or a neurologist working with Dr.

Sherr will communicate such incidental findings with you in person. If returning to UCSF for a findings review is not possible, these results will be communicated using a video and phone conference with Dr. Sherr or another physician in his team. After reviewing the findings with Dr. Sherr, you will be advised to follow up with your primary care physician if you still have further questions and if clinical care is needed to address these findings.

You might feel worried about the possibility of your child's personal information and/or participation in this study not being kept confidential. The risk of unwanted sharing of health information will be minimized by ensuring that all study records that identify your child will be kept completely confidential. A unique study subject number will be used on sample tubes as well as databases containing your child's follow-up testing and questionnaire information. Only select members of the primary research team will have access to the original data. The information you and your child provide will be stored in a locked file cabinet.

There may be risks that are unforeseen and no one knows about yet. The researchers will let you know if they learn anything that might make you change your mind about your child's participation in the study.

For more information about risks, ask one of the investigators or research coordinators.

Are there benefits to taking part in the study?

There will be no direct benefit to your child from participating in this study. This study may help us to understand better behavioral, cognitive, and structural and functional brain anatomy in autism spectrum disorders and/or other neurologic, psychiatric, or behavioral disorders and may support the development of novel therapeutic strategies.

MRI

Your child's brain MRI will be reviewed by a board certified neuroradiologist at UCSF. Whenever an MRI of the brain is conducted, there is a chance that the neuroradiologist will observe an Incidental Finding (IF). An IF is a finding of potential health or reproductive importance and is discovered in the course of conducting research but is beyond the aims of the study.

There may be benefits to learning such results (such as early detection and treatment of a medical condition), but there are risks as well (such as anxiety over a finding for which no treatment is required or appropriate). We will describe three different types of IFs and explain the way that our study manages each type below. All participants will receive a CD/DVD of MRI images to keep. For some participants, a copy of the radiology report prepared by the neuroradiologist reviewing your scan will be included with your CD/DVD. In some cases, you will need to opt-in or opt-out of receiving information about your child's scan by writing your initials in the appropriate space below. You can change your preferences by contacting the research coordinator.

Please remember that the information we collect is for research purposes only and is not meant to replace a diagnostic clinical report as would be provided by your personal physician. We cannot give recommendations except to refer you to your personal clinician (or make a referral if you do not currently have one) so that they can make a more complete assessment.

1. Incidental Finding of Strong Net Benefit

You will be informed of all findings of strong net benefit that may be revealed during your child's imaging procedure. Findings of strong net benefit are likely to uncover a problem that is serious and that may be treatable. For example, if we suspect a condition such as a brain tumor or an aneurysm, the study's neurologist will communicate these findings to you in person. If returning to UCSF for a findings review is not possible, these results will be communicated using a video and phone conference with the study neurologist. After this conference, you will be advised to follow up with your primary care physician if you still have further questions and/or if clinical care is needed to address these findings.

You may choose to have your child's physician informed of IFs of strong net benefit by writing your initials below. Please note, however, that if you choose to have your child's physician informed of any findings of clinical significance, that report will likely be placed in your child's medical record.

Please indicate your preference by writing your initials on the appropriate line:

_____Please inform my doctor of findings on my child's MRI that are likely to be related to a serious health condition

OR

_____Please **do not** inform my doctor of findings on my child's MRI that are likely to be related to a serious health condition

If you **do** wish us to report any findings to your child's physician, you must provide us with the name and location of your child's primary physician, prior to your MRI.

Name of your child's primary physician_____

Contact information_____

2. Incidental Finding of Possible Net Benefit

There is a chance that your child's MRI will reveal an IF of possible net benefit. This type of IF may or may or may not uncover a problem that is real and possibly treatable. An example of this type of IF in a brain MRI is an increase in the number of white matter spots which may have been caused by brain injury, is static and does not require treatment. However, the white matter spots may reveal a treatable condition such as hypertension or type 2 diabetes. Because these findings are of uncertain origin and they may not be treatable, there may be little benefit to learning such results.

You can choose to learn about IFs of possible net benefit that we observe on your child's MRI **OR** you can choose not to receive such results. Please indicate your preference by writing your initials next to the appropriate statement below.

_____I choose to opt-in and receive an MRI report about IFs of possible net benefit.

_____I choose to opt-out of receiving an MRI report about IFs of possible net benefit.

If you chose to opt-in and receive an MRI report about IFs of possible net benefit, the study's neurologist will communicate these findings to you in person. If returning to UCSF is not possible, these results will be communicated using a video and phone conference with the study neurologist. After the conference, you will be advised to follow up with your child's primary care physician if you still have further questions and/or if clinical care is needed to address these findings.

3. Incidental Finding of Unlikely Net Benefit

Some brain MRIs may reveal a condition that is not likely to be of serious health importance or whose health importance is unknown at this time. An example of this type of finding is an arachnoid cyst, or a fluid filled sac located inside the brain or spine. Usually, arachnoid cysts do not have symptoms and do not require treatment. Because arachnoid cysts and other findings of unlikely net benefit are of unknown significance or are known to have no health significance, there may be little to no benefit to learning such results. If the IF is determined to be of unlikely net benefit we will **NOT** provide you with a report of your MRI results.

4. No Findings

Sometimes brain MRIs will not have IFs. If this is the case we will **NOT** provide you with an MRI report.

Neuropsychological Testing

Results of the neuropsychological testing and cognitive assessments done at UCSF will not be shared with the participants. A limited set of neuropsychological testing will be done for research purposes only and is not meant to replace a comprehensive diagnostic clinical assessment. As such, we cannot give any recommendations or interpretations of the data except to refer you to your child's personal clinician (or make a referral if you do not currently have one) so that they can make a more complete assessment.

Blood Sampling:

Results of the blood sampling will not be shared with participants as they are for research purposes only.

What other choices do I have if my child does not take part in this study?

You are free to choose not to have your child participate in the study. If you and/or your child decide not to take part in this study, there will be no penalty to you or your child. Your child will not lose any of his or her regular benefits, and your child can still get care from our institution the way he or she usually does.

Will my child's medical information be kept private?

We will do our best to protect the information we collect about your child. Information that identifies your child will be kept secure and restricted. However, your child's personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your child's name and other identifiers will not be used. Information that identifies your child will be destroyed when this research is complete. Your child's personal information may be given out if required by law. The following organizations may look at information about you in your medical and research records:

- Study Sponsor: Simons Foundation
- UCSF's Committee on Human Research
- Government agencies involved in keeping research safe for people, such as the Food and Drug Administration (FDA).

Sensitive research information: Participation in research may involve a loss of privacy, but information about your child will be handled as confidentially as possible. There is a risk that information about taking part in a study about ASD may influence insurance companies and/or employers regarding your child's health. However, no information obtained in this study will be placed in your child's medical records nor will it be provided to any insurance entity or place of employment, except in the situation described as follows: your child's participation in this study may be noted in your child's medical record at UCSF. If your child does not already have a medical record at UCSF, one will be created for them, since they will be completing some or all of the research activities associated with this study at UCSF's medical center and Pediatric Clinical Research Center (PCRC). Your child's consent forms,

documentation of the blood draw procedure, and/or results of the neuropsychological assessments may be included in this record. Other doctors at UCSF may become aware of your child's participation. However, hospital regulations require that all health care providers treat information in medical records confidentially.

What are the costs of taking part in this study?

There will be no cost to you for any of the study procedures. We will reimburse you for parking costs if your child and you visit UCSF to complete any of the research activities described under the section, "What will happen if my child takes part in this research study?"

Will my child be paid for taking part in this study?

In addition to the study reimbursements outlined above, you will receive compensation in cash or check upon completion of all of the study activities described under the section, "What will happen if I take part in this research study?" You may also be given a prepaid debit card for taking part in this study. We will give you separate instructions on how to use the debit card.

Your child will receive $20 for each blood draw and height, weight, and head size measurements.

Your child will receive $30 for the completion of all surveys and questionnaires

Your child will receive $30 for completion of the in-person psychological assessments.

Your child will receive $60 for completion of all imaging procedures.

What happens if my child is injured because of taking part in this study?

It is important that you tell Dr. Sherr if you feel that your child has been injured because of taking part in this study. You can tell the doctor in person or call (415) 502-8039.

> **Treatment and Compensation for Injury:** If your child is injured as a result of being in this study, treatment will be available. The costs of the treatment may be covered by the University of California, depending on a number of factors. The University does not normally provide any other form of compensation for injury. For further information about this, you may call the office of the Committee on Human Research at 415- 476-1814.

What are my child's rights if they take part in this study?

Having your child take part in this study is your choice. You may choose to have your child take part or not to take part in the study. If you decide to let your child take part in this study, you are free to leave the study at any time. No matter what decision you make, there will be no penalty to you or your child and your child will not lose any of their regular benefits. Leaving the study will not affect your child's medical care. Your child can still get their medical care from our institution. We will tell you about new information or changes in the study that

may affect your willingness to have your child continue in the study. In the case of injury resulting from this study, you will not lose any of your or your child's legal rights to seek payment by signing this form.

Who can answer my questions about the study?

You can talk to the researchers about any questions, concerns, or complaints you have about this study by calling the research staff or Dr. Sherr at (415) 502-8039.

If you wish to ask questions about the study or your child's rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the Office of the Committee on Human Research at 415-476-1814.

What will happen if I agree to donate my specimens?

As part of your child's participation in this research, a tissue sample (blood) will be collected. We would like to keep some of the tissue that is leftover for future research. If you agree, the tissue specimen(s) will be kept in storage in what is called a "tissue bank." Dr. Sherr's tissue bank at UCSF will house tissue specimens collected for the purposes of this research study.

We do not know for sure if your child's tissue specimen(s) or information will be used, but they might be used in research about neurological, psychiatric and behavioral disorders. Your child's specimen(s) and any information about your child will be kept until it is used up or destroyed. If you decide later that you do not want your child's tissue specimen(s) and information to be used for future research, you can notify the investigator and/or a member of the research team by calling (415) 502-8039 and/or in writing, and any remaining identifiable tissue specimen(s) and information will be destroyed if they are no longer needed for your child's care. All written requests should be directed to Elliott Sherr, M.D., Ph.D. at 675 Nelson Rising Lane, Box 3206, San Francisco, CA 94158. However, if any research has already been done using portions of your child's tissue specimen(s), the data will be kept and analyzed as part of those research studies. Reports about research done with your child's tissue will not be given to you or your child's doctor. These reports will not be put in your child's health record. The research will not have an effect on your child's care.

Things to Think About

- The choice to let us keep the leftover tissue specimen(s) for future research is up to you. No matter what you decide to do, it will not affect your child's care.
- If you decide now that your child's tissue specimen(s) can be kept for research, you can change your mind at any time. Just contact us and let us know that you do not want us to use your child's tissue. Then any tissue that remains will no longer be used for research.
- Sometimes tissue specimens are used for genetic research (about diseases that are passed on in families). Even if we use your child's tissue for genetic research, we will not put the results in your child's medical record. The research will not change the care

you receive. Your specimen and any information about you will be kept until it is used up or destroyed. It may be used to develop new drugs, tests, treatments or products. In some instances these may have potential commercial value. Your personal health information cannot be used for additional research without additional approval from either you or a review committee.

- We may give your child's tissue specimen(s) and certain medical information about your child (for example, diagnosis, age, developmental history, etc.) to other scientists or companies not at UCSF, including a controlled access government health research database or the study sponsor (Simons Foundation), but we will not give them your child's name, address, phone number, or any other information that would identify your child. Reports about any research will not be given to you or your child's doctor.
- You will not be charged for donating your child's tissue specimen(s). If any new products, tests or discoveries that result from this research have potential commercial value, you and your child will not share in any financial benefits.
- Your child's personal health information cannot and will not be used for additional research without additional approval from either you or a review committee.
- There is a risk that someone could trace your information and sample back to you. Even without your name or other identifiers, your genetic information is unique to you. The researchers believe the chance that someone will identify you is very small, but the risk may change in the future as people come up with new ways of tracing information.
- In some cases, this information could be used to make it harder for you to get or keep a job or insurance. There are laws against the misuse of genetic information, but they may not give full protection. There can also be a risk in knowing genetic information. New health information about inherited traits that might affect you or your blood relatives could be found during a study. The researchers believe the chance these things will happen is very small, but cannot promise that they will not occur.

Benefits

There is no direct benefit to you or your child for donating your child's tissue specimen(s) and agreeing to have your child's tissue specimen(s) stored and potentially used for research. However, the benefits of research using tissue include learning more about what causes neurological, psychiatric and behavioral disorders and other diseases, how to prevent them, and how to treat them.

Risks

The greatest risk to your child is the release of information from your child's health records. We will do our best to make sure that your child's personal information will be kept private. The chance that this information will be given to someone else is very small.

Making Your Choice

Please read each sentence below and think about your choice. **After reading each sentence, please initial either the "Yes" or "No" box.** If you have any questions, please talk to your doctor or nurse, or call our research review board at 415-476-1814. No matter what you decide to do, it will not affect your child's care.

YES	NO	
		1. My child's tissue may be kept for use in research to learn about, prevent, or treat neurological, psychiatric and/or behavioral disorders.
		2. My child's tissue may be kept for use in research to learn about, prevent or treat other health problems (for example: diabetes, Alzheimer's disease, or heart disease).
		3. Someone may contact me in the future to ask me about whether or not I'm interested in having my child take part in more research.
		4. My child may be videotaped during in-person cognitive testing sessions.

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OPTIONAL: Affiliated Study Data and Sample Linkage

If your child has participated in other studies affiliated with the leading investigator of this study (Dr. Elliott Sherr) OR with the sponsor of the study (e.g. the Simons Foundation, Simons Simplex Collection etc.), there may be opportunities to use previously collected information or biological samples from these prior studies to contribute to this current project. We are also asking for you consent to share the data we collect during this study here at the University of California, San Francisco with the Simons Foundation and the SSC@IAN in order to add to the information that was collected during your participation in the SSC. Please note your decision to indicate your child or your child's family member's participation in other studies is **OPTIONAL and VOLUNTARY. After reading each sentence, please initial either the "Yes" or"No" box**

YES	NO

My child, has participated in other studies affiliated with the leading investigator of this study (Dr. Elliott Sherr) OR with the sponsor of the study (Simons Foundation, Simons Simplex Collection).

Name of Study: _____

_____

YES	NO

I allow the research team to **obtain** and use my child's information/biological samples, previously collected from other studies affiliated with the leading investigator of this study (Dr. Elliott Sherr) OR with the sponsor of the study (Simons Foundation, Simons Simplex Collection).

YES	NO

I allow the research team to **share** information/biological samples obtained about me during this study to be made available to the Simons Foundation. Data that will be shared may include, identifying information, demographic information, survey measures, medical history, body measurements, and data derived from the collected blood sample.

Please note that it is not required for your child's participation to indicate whether or not they participated in another study.

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CONSENT

You have been given copies of this consent form and the Experimental Subject's Bill of Rights to keep. You will be asked to sign a separate form authorizing access, use, creation, or disclosure of health information about your child.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which your child is otherwise entitled.

1. Parent/Legal Guardian Signature

The person being considered for this study is unable to consent for him or herself because he or she is a minor. By signing below, you are giving your permission for your child to be included in this study.

Date	Signature of Parent/Legal Guardian	Print Name
	Relationship to Minor Participant	Name of Minor Participant

2. Study Staff Signature

Date	Signature of Person Obtaining Consent	Print Name of Person Obtaining Consent