

UNIVERSITY OF CALIFORNIA SAN FRANCISCO (UCSF) CONSENT TO BE CONTACTED FOR FUTURE RESEARCH

Sensory Neurodevelopment & Program (SNAP) Departments of Pediatrics, Psychiatry, Neurology, Radiology & Genetics

What is the purpose of this consent? The doctors in the Sensory Neurodevelopment & Autism Program (SNAP) at UCSF are doing research that is designed to lead to better understanding and treatments for autism spectrum disorders (ASDs) and neurodevelopmental disorders (NDDs). They would like to inform you about the ongoing research at UCSF that may be of interest to you and your family. By signing this form, you will be allowing the team of professionals from the UCSF Sensory Neurodevelopment & Autism Program's research labs to contact you in the future to ask if you and your child are interested in hearing more about new studies. You have no obligation to actually participate in any studies.

What happens if I type my name on this form? If you sign this consent, you are giving authorization for the information that you will be filling out online to be put into a secure research database. This includes information about your child's diagnosis, name, date of birth, and contact information. This information will be kept indefinitely, unless you withdraw your permission. If a study that includes individuals with your child's diagnosis needs participants, you may be contacted to determine if the study is right for your child at this time. You may withdraw permission to be contacted at any time by contacting the SNAP database coordinator @ (415) 640-2680.

What happens if I don't type my name on this form? Declining to participate will have no influence on your child's present or future clinical care at UCSF. There will be no penalty or loss of benefits to which you and your child are otherwise entitled.

Are there any risks to typing my name on this form? Participation in research may involve some loss of privacy. However, your child's records will be handled as confidentially as possible. Access will be limited to the data manager and the SNAP study team and will require a password. No information will be used for research without additional permission. Your contact information will not be shared with anyone outside of this program.

Are there any financial considerations? There will be no cost or payment if you sign this form.

What do I do if I have questions, now or later? You can talk with the study researcher about any questions, concerns or complaints you have about this study. You may contact the study principle investigator, Elysa Marco MD @ (415) 640-2680. If you wish to ask questions about the study or your 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 do I do to consent? If you would like to be included in our research registry and be contacted for studies in the future please complete and electronically sign the online SNAP registry form. Please print a copy or save this consent for your records. Please note that only parents, legal guardians and/or conservators are allowed to sign on behalf of a pediatric research registry participant.