UC San Diego Eating Disorder Center for Treatment and Research Registry

Who is conducting the study, why your child been asked to participate, how your child was selected, and what is the approximate number of participants in the study?
Dr. Christina Wierenga and associates are conducting a research study to find out more about eating disorders. Your child have been asked to participate in this study because your child has either never had an eating disorder, has been recovered from an eating disorder or currently has an eating disorder. There will be approximately 5,000 individuals consented to join this registry.

Why is this study being done?
The purpose of this study is to recruit individuals who may be eligible for our research studies now or in the future. Our research is primarily designed to understand more about the neurobiology and treatment of eating disorders. This research seeks to answer questions that could improve treatment and provide better education about eating disorders.

What will happen to your child in this study and which procedures are standard of care and which are experimental?
If you agree to allow your child to participate in this study, the following will happen to your child: they will be asked a few questions about their age, sex, overall health, eating disorder status, and provide contact information. By agreeing to be part of this registry, you are agreeing that you and your child will receive email notifications about research studies that are actively recruiting participants. You and your child have the right to refuse to participate in any of these studies.

What are the alternatives to participating in this study?
Taking part in this registry is voluntary. The alternative is to not participate in our registry. Whether or not your provide consent for your child to participate in this registry will have no effect on your or your child’s current or future relationship with the University, nor will it have any effect on your or your child’s current or future medical care at a UCSD hospital or an affiliated health care provider.

What benefits can be reasonably expected?
There are no direct benefits for having your child enroll in this research volunteer registry, beyond being the first to learn of opportunities to participate in research studies that are being conducted at the UC San Diego Eating Disorders Center for Treatment and Research. Again, participation in both the research registry and any of the research studies advertised through the registry is completely voluntary.

Can you choose to not to have your child participate or withdraw from the study without penalty or loss of benefits?
Participation in research is voluntary. You may refuse to allow your child to participate or withdraw your child at any time without penalty or loss of benefits to which you or your child are entitled. If you decide that you no longer want your child to continue in this registry, your child will be requested to please email edresearch@health.ucsd.edu to inform us that they want to withdraw and their information will be removed from the registry.

You and your child will be told if any important, new information is found during the course of this study that may affect your decision to continue participation.

**Will you be compensated for participating in this study?**
You and your child will not be compensated for participating in this registry. However, they may be compensated for studies in which they are eligible for.

**Are there any costs associated with participating in this study?**
There will be no cost to you or your child for participating in this study.

**What about your confidentiality?**
Research records will be kept confidential to the extent allowed by law. Your child’s information will be in a secured electronic database protected by password. The only people who will have access to this database are trained researchers and research assistants. The UCSD Institutional Review Board may review research records.

**Who can you call if you have questions?**
If you have other questions or research-related problems, you may reach Dr.Wierenga at 858-543-8047.
You may also call the Office of IRB Administration (OIA) at 858-246-4777 to inquire about your rights as a research subject or to report research-related problems.

**Your Signature and Consent**
You have received a copy of this consent document and a copy of the “Experimental Subject's Bill of Rights” to keep.

You agree to allow your child to participate.

____________________________________   ____________________
Parent/Guardian Signature                Date

____________________________________   ____________________
Parent/Guardian Signature of Second Parent Date
(if required by IRB)