

UC San Diego Eating Disorder Center for Treatment and Research Registry

Who is conducting the study, why you have been asked to participate, how you were selected, and what is the approximate number of participants in the study?

Dr. Christina Wierenga and associates are conducting research studies to find out more about eating disorders. You have been asked to participate in this study because we want to compare individuals who have never had an eating disorder with those who have a history of eating disorders, and you fall into one of these categories and have expressed interest in being in one of our research studies now or in the future. 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 you in this study and which procedures are standard of care and which are experimental?

If you agree to be in this study, the following will happen to you: you will answer a few questions about your age, sex, overall health, eating disorder status, and you provide your contact information. By agreeing to be a part of this registry, you are agreeing to receive email notification about research studies that are actively recruiting participants. You have the right to refuse to participate in any of these studies.

How much time will each study procedure take, what is your total time commitment, and how long will the study last?

Taking part in the registry will take about 5-10 minutes. Your name will remain in the registry unless you asked to be removed. The studies in which you are eligible for may vary from 30 minutes to 4 hours.

What risks are associated with this study?

Participation in this study may involve the risk of loss of confidentiality. The registry will contain personal information such as your weight, gender, and eating disorder status, and there is a possibility of a loss in confidentiality. However, we have taken several precautions to protect your confidentiality, such as keeping our paper files in locked cabinets, and our electronic database secured with a password.

What are the alternatives to participating in this study?

Taking part in this registry is voluntary. The alternatives is to not participate in our registry. Whether or not you provide consent to participate in this registry will have no effect on your

current or future relationship with the University, nor will it have any effect on your current or future medical care at UCSD hospital or affiliated health care provider.

What benefits can be reasonably expected?

There are no direct benefits for enrolling in the 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 Treatment and Research Center. Again, participation in both the research volunteer registry and any of the research studies advertised on the registry is completely voluntary.

Can you choose to not participate or withdraw from the study without penalty or loss of benefits?

Participation in research is voluntary. You may refuse to participate or withdraw at any time without penalty or loss of benefits to which you are entitled. If you decide that you no longer wish to continue in this study, please email edresearch@ucsd.edu to inform us, and your information will be removed from the registry.

You will be told if any important new information is found during the course of this study that may affect your decision to continue being in the registry.

Will you be compensated for participating in this study?

You will not be compensated for participating in the registry. However, you may be compensated for studies in which you are eligible for.

Are there any costs associated with participating in this study?

There will be no cost to you for participating in this study.

What about your confidentiality?

Research records will be kept confidential to the extent allowed by law. Your 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 Human Research Protections Program Office at 858-246-HRPP (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 participate.

Subject's signature

Date