

SUBJECT'S CONSENT FORM

Project Title: THE DNA SHOAH PROJECT

You are being asked to read the following material to ensure that you are informed of the nature of this research study and of how you will participate in it, if you consent to do so. Signing this form will indicate that you have been so informed and that you give your consent. Federal regulations require written informed consent prior to participation in this research study so that you can know the nature and risks of your participation and can decide to participate or not participate in a free and informed manner. If you choose not to participate, your refusal will involve no penalty or loss of benefits which you would normally experience.

PURPOSE

You are being invited to participate voluntarily in the above-titled research project. The purpose of this project is to establish a database of genetic markers for families who lost relatives during the Holocaust. This database will serve to assist (1) in the identification of Holocaust victims whose remains continue to surface in Europe, and (2) global orphan-placement organizations to identify siblings and close relatives separated by World War II. The genetic markers to be studied include both single nucleotide polymorphisms (SNPs) and short tandem repeats (STRs) on the autosomes and Y chromosome, as well as mitochondrial DNA sequences

SELECTION CRITERIA

The Principal Investigator or a member of his/her study staff will discuss the requirements for participation in this study with you. To be eligible to participate, you must be related to a victim of the Holocaust.

PROCEDURE(S)

The following information describes your participation in this study. You will be asked to (1) fill out ancestry information forms and (2) use a cytology brush to brush the inside of each cheek for 20 seconds. This is just like brushing your teeth except on the inside of your cheek. The cytology brush will then be transferred to a storage solution until your DNA can be extracted and analyzed.

RISKS

The procedure for collecting your DNA is completely safe. The results of the genetic testing, however, could indicate that family relationships may not be what you have believed.

BENEFITS

There is no direct benefit to you from your participation. Your participation will contribute to a growing database that may eventually be useful for identifying victims of the Holocaust.

CONFIDENTIALITY

The data from this project are only available to Michael Hammer, Ph.D. and his project staff. Data are completely confidential. The information will not be shared with any other non-forensic agency. The anonymity of those in the database will be assured by coding of names. Any

publications or reports will not identify you by name. Data will not be used for any purpose other than identifying Holocaust victims and living siblings or closely related individuals. Representatives of regulatory agencies (including the University of Arizona Human Subjects Protection Program) may access your records to ensure quality of data and study conduct.

PARTICIPATION COSTS AND SUBJECT COMPENSATION

There is no cost to you for participating except your time. You will not be compensated for your participation.

CONTACTS

You can obtain further information about the research or voice concerns or complaints about the research by calling the DNA Shoah Project office at (520) 626-6203 or (866) 897-1150 (toll-free). If you have questions concerning your rights as a research participant, have questions, complaints or concerns about the research and can't reach the Principal Investigator, or want to talk to someone other than the Investigator, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state, use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program by email, please use the following email address: <http://www.irb.arizona.edu/contact/>.

LIABILITY

Side effects or harm are possible in any research program despite the use of high standards of care and could occur through no fault of yours or the investigator involved. Known side effects have been described in this consent form. However, unforeseeable harm also may occur and require care. You do not give up any of your legal rights by signing this form. In the event that you require or are billed for medical care that you feel has been caused by the research, you should contact the DNA Shoah Project office at (520) 626-6203 or (866) 897-1150 (toll free).

AUTHORIZATION

Before giving my consent by signing this form, the methods, inconveniences, risks, and benefits have been explained to me and my questions have been answered. I may ask questions at any time and I am free to withdraw from the project at any time without causing bad feelings or affecting my medical care. My participation in this project may be ended by the investigator or by the sponsor for reasons that would be explained. New information developed during the course of this study, which may affect my willingness to continue in this research project will be given to me as it becomes available. This consent form will be filed in an area designated by the Human Subjects Protection Program with access restricted by the principal investigator, Michael Hammer, Ph.D. or authorized representative of the ARL Division of Biotechnology. I do not give up any of my legal rights by signing this form. A copy of this signed consent form will be given to me.

Subject's Name (PRINT)

Subject's Signature

Date

INVESTIGATOR'S AFFIDAVIT:

Either I have or my agent has carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who signed this consent form was informed of the nature, demands, benefits, and risks involved in his/her participation.

Interviewer's Signature

Interview Date

Interviewer Name

Principal Investigator or Co-PI

Interview Number

Contributor's Name

Contributor's Phone Number

Interview Event / Location

Place bar code here
