University of Minnesota

Assent to Participate in Research Ages 12-17

Title of Research Study: Ten Thousand Families Study (STUDY00000877)

Investigator Team: Jenny N. Poynter, PhD, Principal Investigator

Sponsored By: Co-sponsored by University of Minnesota Masonic Cancer Center, the Coordinating

Center for Biometric Research, and the University of Minnesota Academic Health Center.

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Who is paying for the study? The project is paid for by the National Institutes of Health, the University of Minnesota Masonic Cancer Center, the Coordinating Centers for Biometric Research, and the University of Minnesota Academic Health Center.

What is health research?

Health research is research that focuses on improving the quality of life and extending the life of those with illnesses. Research consists of making educated guesses called hypotheses about how the world works and testing those hypotheses by collecting data. The goal is to learn new things about our world.

Why am I being asked to take part in this research study?

You are being asked to take part in this research study because someone in your family is also participating. Researchers will use the information from your family to learn why some people get diseases and others stay healthy.

What should I know about being in a research study?

You do not have to be in this study if you do not want to do so. It is up to you if you want to participate. Talk to your parent about any questions or concerns you have about the study. You can agree to take part and change your mind later. If you decide you do not want to be in this study, no one will be mad at you. You can ask all the questions you want before you decide.

Why is this research being done?

In this study, we want to find out more about staying healthy.

How long will the research last?

10,000 Families is an ongoing study and will continue as long as you and your parent agree.

What happens if I say "Yes, I want to be in this research"?

We will do the following:

- Measure your height, weight and waist
- Check your blood pressure

- Collect some hair, fingernails or toenails from you
- Collect some blood from you (optional)
- Collect some urine from you
- Ask you to wear a wristband for 7 days and send it back to us
- We may collect some saliva (also called spit) from you
- We may also measure your hand strength and check your hearing and heart
- Ask your parent to complete some questions about your health.
- Invite you to complete a survey, which includes questions about skincare, smoking, drinking, drug use, gender identity, sexual behavior, diet, physical activity, and other experiences. We will invite you to complete it each year until you turn 18. Each time you will receive a \$5 e-giftcard.
- Future contact: If you provide your email address and a cell phone number when we invite you to
 complete the survey, we will use email and text messages to send reminders about the annual
 survey and to invite you to continue in the study after you turn 18. We cannot guarantee the
 confidentiality of text messages, which means text messages should not include any private
 information about you or your health.

Is there any way being in this study could be bad for me?

We will ask your parent to complete some questions about your health which could cause you to feel uncomfortable. The questions we will ask you in the survey each year might make you feel uncomfortable. You do not have to answer any question that makes you feel uncomfortable. We will ask you for an optional blood sample. Drawing blood can cause bruising, pain, fainting, temporary bleeding or infection. You do not have to complete the blood draw.

What happens to the information collected for the research?

The researchers will share your information, including research study records, to only those people who need to review it. For example, sometimes researchers need to share information with the University or other people that work in research to make sure the researchers are following the rules.

All information you or your parent provide as part of 10,000 Families is confidential. To help protect your privacy, the National Institutes of Health (NIH) has granted a Certificate of Confidentiality (CoC). You can find the CoC language here [insert weblink] on our website.

Who can I talk to?

For questions about research appointments, the research study, research results, or other concerns, call the study team at:

Researcher Name: Jenny N. Poynter, PhD

Department of Pediatrics Phone Number: 612-626-2902

Email Address: poynt006@umn.edu

Study Staff (if applicable): Andrea Hickle, MPH

Phone Number: 612-301-2726 Email Address: <u>TenKFS@umn.edu</u>

To reach the research team: Please see the "Investigator Contact Information" section above.

To reach someone outside of the research team: This research has been reviewed and approved by an Institutional Review Board (IRB), a group of people that look at the research before it starts. This group is part of the Human Research Protection Program (HRPP). To share concerns privately with the HRPP about your research experience, call the Research Participants' Advocate Line at 612-625-1650 (Toll Free: 1-888-224-8636) or go to z.umn.edu/participants. You are encouraged to contact the HRPP if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You are having difficulty reaching the research team.
- You want to talk to someone besides the research team or your parents.
- You have questions about your rights as a research participant.
- You want to get information or provide feedback about this research.

Signature Block for Child Assent

Signature of child	Date
Printed name of child	
Printed name of person obtaining assent	 Date