

RAYS: Rural Youth and Adult Sun Protection Study (Parents) Consent Cover Letter

SUMMARY

- You are being asked to take part in a research study (RAYS). Your participation in this study is completely voluntary.
- The purpose of RAYS is to improve use of sun protective behaviors among youths living in rural communities in Utah and West Virginia.
- Your participation in this study will last about 15 months and will include receiving information about sports injury prevention or skin cancer prevention.
- You will be asked to complete 3 questionnaires about you and your family.
- The risks associated with study participation are minimal.
- If you decide you no longer want to participate in this study, you can contact us at any point and we will not collect any more information from you.
- We cannot guarantee any direct benefits to you, however, as compensation for your participation in the study you will receive up to \$450 in gift cards for completing questionnaires and other study-related activities.

BACKGROUND

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Take time to decide whether or not to volunteer to take part in this research study.

The purpose of this study is to help prevent skin cancer. The goal of the study is to improve use of sun protective behaviors among youths living in rural communities in Utah and West Virginia. The lead investigators for this study are Dr. Yelena Wu from the University of Utah and Huntsman Cancer Institute, Dannell Boatman from West Virginia University and Dr. Kenneth Tercyak from the Lombardi Comprehensive Cancer Center at Georgetown University.

STUDY PROCEDURES

Your child will be on a team which may be enrolled in the study. We are studying ways to train coaches on educating their players on creating healthy habits during sports. Your child's sports league will be randomly assigned (like flipping a coin) to one of the two training types. This will help us compare the two trainings to see if one is more effective than the other. Your child's sports coach will receive training from study staff on general sports injury prevention principles or on information related to skin cancer prevention. You are also going to receive similar information. Your child's team and sports league may be provided with sun safety supplies (e.g., sunscreen, hats, shade tent, sun-safe uniforms, sunglasses) and information. We will observe the sun protection behaviors of your child and their teammates during team meetings, practices, or games which our study team may video record. You may be asked to fill out a questionnaire about you and your family. The questionnaire could ask about things that you and/or your child do related to skin cancer prevention, and your child's tanning and sunburn history. You may be asked to complete a total of 3 questionnaires: one today, one at the end of the sports season and one approximately a year later. At the conclusion of the study, you may be contacted by the research



staff for a brief interview for your feedback on your experience. Study activities listed above may be video or audio recorded for later analysis by the study team. You may be contacted about study activities via email, text messages, or phone calls.

RISKS

The risk or discomforts associated with participating in this study are minimal. If you feel upset from any part of this experience, you can tell the researcher, who will tell you about resources available to help. Even though we do everything we can to protect the identity and privacy of participants, there is still a risk that data could be traced back to an individual. Once data is shared, participants can still request that their data be removed from data repositories. However, some data that have been distributed for approved research use cannot be retrieved.

BENEFITS

While there are no direct benefits to you for participating in this study, you may gain awareness that you are contributing to new knowledge that may benefit others in rural communities who are at risk for skin cancer in the future.

PERSON TO CONTACT

If there is anything that is not clear or if you would like more information, you can e-mail the research staff at rays.study@hci.utah.edu. If you have any complaints or concerns about this study, you can contact Dr. Yelena Wu by leaving a message at (801) 585-9427. If you feel you have been harmed as result of participation, please call Dr. Yelena Wu at (801) 585-9427, who may be reached Monday through Friday, 8am-5pm.

Institutional Review Board: Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Research Participant Advocate: You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

VOLUNTARY PARTICIPATION

If you change your mind, you can tell us anytime that you do not want to be in this study. We will not be able to collect new information about you, and you will be withdrawn from the research study. However, we can continue to use information we have already started to use in our research, as needed to maintain the integrity of the research.

COSTS AND COMPENSATION TO PARTICIPANTS

There is no cost for participating in this study. You will be compensated up to \$100 for your participation in completing study surveys and the optional post-study telephone interview. You will receive \$20 for completing survey #1 (soon), \$30 for completing survey #2 at the end of the sports season, \$30 for completing survey #3 approximately one year later, and \$20 for completing the optional telephone interview. You also have the opportunity to be entered into a raffle to win an additional \$250. You may



be asked to support study activities by helping record a few short videos of your child's games or practices and completing a short survey regarding what you see. If you are selected to help with these videos you will be compensated \$25 per game recorded. Compensation will be provided to you directly following each study activity or questionnaire that you complete. If you do not complete all of the questionnaires or the final interview, your compensation will be prorated for the activities you did complete. Parents have the chance to earn extra gift cards for being a RAYS ambassador and encouraging other parents to participate in the study. Parents interested in this opportunity can reach out to study staff. Compensation will come in the form of cash-equivalent gift cards that may be physical or digital; if digital, this gift card will be issued to you by email. If your team is randomized to receive sun safety supplies, your child may be able to keep some of the supplies after the season ends (e.g. sunglasses, hat, sun-safe uniform).

AUTHORIZATION FOR USE OF YOUR PROTECTED HEALTH INFORMATION

Agreeing to this document means you allow us, the researchers in this study, and others working with us to use some information about your health for this research study. We will share information that identifies you and your child with our research team members at the University of Utah at Huntsman Cancer Institute, Georgetown University at Lombardi Cancer Institute, West Virginia University.

This is the information we will use and include in our research records:

- Demographic and identifying information such as name, gender, age, race, level of schooling, family medical history, and occupation.
- The information provided to us on the study questionnaires
- We may video and/or audio record games, practices, education sessions, post-study interviews or other study activities for data analysis.

How we will protect and share your information:

- We will do everything we can to keep your information private but we cannot guarantee this. Study information will be kept in a secured manner and electronic records will be password protected. Your data will only be used for the present study and will not be save or shared for future research.
- If we share your identifying information with groups outside of the University of Utah at Huntsman Cancer Institute, they may not be required to follow the same federal privacy laws that we follow. They may also share your information again with others not described in this form.
- In order to conduct this study and make sure it is conducted as described in this form, the research records may be used and reviewed by others who are working with us on this research:
 - Members of the research team and Huntsman Cancer Institute;
 - The University of Utah Institutional Review Board (IRB), which reviews research involving people to make sure the study protects your rights.



This authorization does not have an expiration date.

CONSENT

I confirm that I have read this consent and authorization document and have had the opportunity to ask questions. **I agree to take part in this research study and authorize you to use and disclose health information about me and my child for this study, as you have explained in this document.**

We may contact you about future research that may be of interest to you or for other matters related to this study.

We greatly appreciate you participating in our study.

