

Appendix G
TAR Consent Forms

Flesch-Kincaid Read Level: 8.9; with agency name, contractor name, “vermiculite”, “asbestos”, and “tremolite” removed is 7.7.

Consent Statement (Adults)

The Agency for Toxic Substances and Disease Registry (ATSDR) is making a registry of people who may have been exposed to asbestos in Libby,

Montana. This registry is called the Tremolite Asbestos Registry, or TAR.

You are being asked to take part because you belong to at least one of these groups:

- You are a former vermiculite worker employed in Libby.
- You lived with a former vermiculite worker while he/she worked at the mine.
- You lived, worked or went to school in Libby for at least 6 months before 12/31/1990.
- You took part in activities in Libby that brought you into close contact with the vermiculite mine, mill, or material for at least 6 months before 12/31/1990.

The purpose of the TAR is to follow the health of people exposed to asbestos. We would like to ask questions about your health and your possible exposure to asbestos. The answers you give will be kept in the TAR. Using your answers along with answers from other TAR members, health experts can study possible health problems from asbestos that came from the Libby vermiculite mine. ATSDR will also use the TAR to keep

you informed about new data on asbestos-related disease. The survey will take about 30 minutes of your time.

Taking part in this research study is your choice. There are no physical risks involved. However, you may feel uneasy answering some of the questions. The benefits of taking part include being kept informed of new research on asbestos-related disease and programs that are available to you. No medical care will be given as part of this study.

If you do not want to answer any question, you can skip it. You can also stop the interview at any time. If you stop the interview, it will not change any benefits that you might receive. All answers you give will be kept private to the extent allowed by law. The data may be shared with other researchers for legitimate research purposes, but it will not include information that will personally identify you. No facts that name you or where you live will be put in any report. You may be asked to take part in future surveys for the registry every three years. Taking part in future surveys is also your choice.

If you have questions about the study itself or your rights, I have some phone numbers you can call. If you have any questions about the study, please call Mr. Ted Larson, the project's principal investigator, at 1-888-422-8737. If you have any questions about your rights as a person in this study, or feel you have been harmed by this study, please call Annie Latimer, ATSDR's Human Subjects Contact, at 800-232-4636, leave a message including your name and phone number, and someone will call you back as soon as possible.

Do you confirm that I have described the purpose of this study and that you understand your rights if you take part?

Yes No Signature of Interviewer_____ Date _____

Do you agree to take part in the Tremolite Asbestos Registry?

Yes No Signature of Interviewer_____ Date _____

We will be asking you questions about your health. In the future, ATSDR may ask you for your written permission to contact your health services provider to verify your answers to the questions about your health. It is your choice to take part in additional parts of the project. If you decide not to

give permission to ATSDR to contact your health services provider, it will not affect your taking part in the Registry.

Do you understand that ATSDR may ask for your written permission to contact your health services provider?

Yes No Signature of Interviewer_____ Date _____

If you took part the free screening that ATSDR offered in Libby in 2000, ATSDR is would like to add that information to the TAR as well. The information collected in 2000 may have included chest x-ray and spirometry (breathing test) results. ATSDR may contact you in the future to ask your permission to add this information to the TAR. It is you choice to have this information added to the TAR. If you decide not to permit ATSDR to add this information, it will not affect your taking part in the Registry.

Do you understand that ATSDR may ask for your written permission to add your screening information to the TAR?

Yes No Signature of Interviewer_____ Date _____

Flesch-Kincaid Read Level: 8.9; with agency name and words “vermiculite”, “tremolite”, and “asbestos” removed is 7.7.

Consent Form/Statement (Children)

The Agency for Toxic Substances and Disease Registry (ATSDR) is making a registry of people who may have been exposed to asbestos in Libby, Montana. This registry is called the Tremolite Asbestos Registry, or TAR. Your child is being asked to take part because he/she belongs to at least one of these groups:

- Your child lived with a former Libby vermiculite worker while the worker was employed at the mine.
- Your child lived, worked or went to school in Libby for at least 6 months before 12/31/1990.
- Your child took part in activities in Libby that brought him/her into close contact with the vermiculite mine, mill, or material for at least 6 months before 12/31/1990.

The purpose of the TAR is to follow the health of people exposed to asbestos. We would like to ask you questions about your child’s health and his/her possible exposure to asbestos. The answers you give about your child will be kept in the TAR. Using your answers along with answers from other TAR members, health experts can study possible health problems from asbestos that came from the Libby vermiculite mine. ATSDR will also use

the TAR to keep you informed about new data on asbestos-related disease.

The survey will take about 30 minutes of your time.

Taking part in this research study is your choice. There are no physical risks involved for your child if you take part in this study. However, you may feel uneasy answering some of the questions. The benefits of taking part include being kept informed of new research on asbestos-related disease and programs that are available to you. In addition, if you decide to take part, you will be helping study the health of former vermiculite workers, their families and Libby community members. No medical care will be given as part of this study.

If you do not want to answer any question, you can skip it. You can also stop the interview at any time. If you stop the interview, it will not change any benefits that your child might receive. All answers you give will be kept private to the extent allowed by law. The data may be shared with other researchers for legitimate research purposes, but it will not include information that will personally identify you or your child. No facts that name you or your child or where you or he/she lives will be put in any report. Your child may be asked to take part in future surveys for the

registry every three years. Taking part in future surveys is also your choice. When your child reaches age 18, he or she can choose whether to continue taking part in the TAR. He/she can also choose to have his/her data removed from the TAR at that time.

If you have questions about the survey itself, or your child's rights if you take part, I have some phone numbers you can call. If you have any questions about the study, please call Mr. Ted Larson, the project's principal investigator, at 1-888-422-8737. If you have any questions about your rights as a person in this study, or feel you have been harmed by this study, please call Annie Latimer, ATSDR's Human Subjects Contact, at 800-232-4636, leave a message including your name and phone number, and someone will call you back as soon as possible.

Do you confirm that I have described the purpose of this study and that you understand your and your child's rights if you take part?

Yes No Signature of Interviewer _____ Date _____

Do you agree for your child to take part in the Tremolite Asbestos Registry?

Yes No Signature of Interviewer_____ Date _____

We will be asking you questions about your child's health. In the future, ATSDR may ask you for your written permission to contact your child's health services provider to verify your answers to the questions about your child's health. It is your choice to take part in this part of the project. If you decide not to give permission to ATSDR to contact your child's health services provider, it will not affect your child's taking part in the Registry.

Do you understand that ATSDR may ask for your written permission to contact your child's health services provider?

Yes No Signature of Interviewer_____ Date _____

If your child took part the free screening that ATSDR offered in Libby in 2000, ATSDR is would like to add that information to the TAR as well. The information collected in 2000 may have included chest x-ray and spirometry (breathing test) results. ATSDR may contact you in the future to ask your permission to add this information to the TAR. It is you choice to have this information added to the TAR. If you decide not to permit ATSDR to add this information, it will not affect your child's taking part in the Registry.

Do you understand that ATSDR may ask for your written permission to add your child's screening information to the TAR?

Yes No Signature of Interviewer _____ Date _____